



Collected Works of Paul Hunt

Edited with commentary by Luke Beesley

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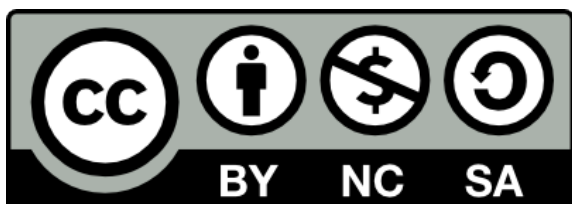
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About This Book

Paul Hunt is often described, with good reason, as the founder of the disabled people's movement in Britain. He was a critical voice in the disability campaigns of the 1960s, which were often driven by non-disabled people, and started the Union of the Physically Impaired Against Segregation (UPIAS); probably the most influential organisation in disability politics in Britain. Despite this, the vast majority of his writings were unavailable for decades. This collection brings together Hunt's out of print, or previously unpublished, writings into a single collection – using material held in the **Leonard Cheshire Rewind Archives**, and the **Judy and Paul Hunt Collection** and **Disabled People's Archives** at Manchester Central Library. We are grateful to the Leonard Cheshire Archive Team, the Archive Steering Group at the Greater Manchester Coalition of Disabled People, and Peter Owens Publishers for allowing us to reproduce that material here. We are also grateful to the Archives+ team in Manchester for support with accessing Hunt's writings.

We understand that readers will approach this collection for different reasons. Our main concern has been putting Hunt's work in the context of his times: these were decades when disability became a public issue, and where the meanings and the politics of disablement were first seriously contested in Britain. Unfortunately, this period has suffered the same fate as Hunt, and it is only recently that serious historical research has begun to investigate the birth of disability as a matter of public and government concern in the '60s and early '70s. A long introductory essay ties together Hunt's biography, the changing landscape of disability campaigns and services, and the development of his ideas over the course of his life.

Other readers will be interested in the particular movements, campaigns, and organisations that Hunt was involved in. We have divided his writings into seven sections, each with a short introduction to put specific articles in their context. These

sections are based on themes in Hunt's work, and are roughly divided between the writings he did outside of UPIAS, and writings from within the organisation. The first two of these sections concern struggles between residents, staff, and managers in the Leonard Cheshire Foundation for the Sick in the first half of the 1960s. The third collects Hunt's writings on institutions and deinstitutionalisation before UPIAS's first conference. The fourth is all of Hunt's columns from **The Cheshire Smile** – the quarterly magazine of the Cheshire Foundation –, and cover a wider variety of topics. The fifth section collects Hunt's writings on the Disablement Income Group before resigning from the organisation. The final two sections concern Hunt's work with UPIAS; section six contains Hunt's writings in UPIAS between its founding in 1972 and 1977 – shortly after **Fundamental Principles of Disability** (the second of UPIAS's two policy documents-cum-manifestos) was written. The final section is Hunt's side of an argument with Vic Finkelstein over whether UPIAS should be wound-up after it had entered an organisational crisis. For the reader's ease, the editorial introductions to each section are in a different print to the main texts.

The commentary on this collection provides detailed notes on people, organisations, or books and articles mentioned by Hunt in his writings. For ease of reading, this commentary is in endnotes at the end of the book. If you are using the digital edition, you can either double click the number referring to an endnote, or select it with your screen reader, to be taken straight to the relevant note.

Texts have been selected for this collection based on whether they shed light on the development of Hunt's thought and the changing ways in which disability was understood during his life-time. We have, however, been reluctant to reproduce work which is already (or shortly will be) widely available – especially when this involves removing it from its context. On this basis, we have left out Hunt's statement of UPIAS's policy in **Fundamental Principles of Disability**, and his essay **A Critical Condition** from 1966 – which will soon be republished

in a new edition of the book **Stigma**, which Hunt edited and in which it was originally published.

In line with the privacy policy of the UPIAS Collection in the **Disabled People's Archives**, all references to UPIAS members in texts from this collection have been anonymised unless these references discuss events that are already in the public domain, or explicit permission has been given to name that member by their surviving friends and family.

The texts in this collection were written between 1958 and 1979. Some of the language commonly used at this time is outdated and offensive today. Where offensive terms are included in the text, a commentary note explains their context in the language of the time.

The editor was supported by a stipend from the Techne Doctoral Partnership while completing this work.

Editor's Introduction

Who was Paul Hunt?

It's often said that British society 'discovered' disabled people in the 1960s; as if disability, like gravity or crude oil, had always been around but only just been noticed. The truth is that disabled people forced themselves into public view; a group who'd been set apart from society in hospitals and asylums, excluded from education, work, and decent housing, and who had stayed poor while most people got richer, finally stopped keeping quiet. They would no longer be grateful for whatever they were given.

They were joined by a host of modern professionals: social workers, rehabilitation specialists, Occupational Therapists, academics, and charity leaders offering new kinds of hospitals, treatments, care homes, and day centres. On the face of it, these (usually non-disabled) workers were in complete agreement with them; the housing, services, benefits, and opportunities available to disabled people were demeaning and de-humanising, and disabled Britons deserved all the freedoms and privileges of their non-disabled countrymen. There was a catch, though; something must be done, but professionals believed they should be the ones doing it. They, after all, had the most up to date knowledge about disability (often with qualifications to prove it). But these new professionals also thought they knew disabled people's problems better than disabled people themselves. While disabled people joined campaign groups, professionals often dominated the actual

campaigning; making the important decisions and benefitting most from the higher public profile of disability issues.

If we fast forward twenty years, the picture changes. The professionals of the '60s did well for themselves; their charities, research centres, and job roles became fixed parts of Britain's social services and welfare system. But they no longer had things all their own way. Where the most radical disabled people had once looked to professionals for solutions to inequality, poverty, and discrimination; by the mid-1980s they saw those professionals' solutions as part of a bigger problem – the segregation of disabled people from mainstream society. All around the country, they either demanded control over professionally run services and organisations, or set up their own to rival them. They organised national and international networks of activists, shared ideas, tactics, and strategies, and forced their opponents to negotiate with them on their own terms.

The story of how that social movement was built is the story of hundreds, perhaps thousands, of disabled activists struggling to change their lives and the world as they found it. It's also a story about failed reform campaigns led by professionals, and the turbulent economic and political background these played out against. However that story is told, it's impossible to leave out Paul Hunt. Hunt was deeply involved in the old, professional led, movements for disability justice; developing a platform in its press as the voice of the disabled grassroots. He was also one of the first to realise that something was deeply wrong in the alliance between professional reformers and disabled people, and to see the need for disabled people to work out their own understanding of why they were excluded from society and to take action together without asking anyone else's permission. Hunt had the vision to see that democratic organisations **of** disabled people could be more than just a part of campaigns over which their members had little control. He founded the Union of the Physically Impaired Against Segregation (UPIAS), a disabled people's organisation of a new type – not divided by kinds of impairment nor restricted to

acting on one kind of issue; concerned with building a militant movement rather than finding compromises with professionals and the state.

Until very recently, we've known little more than that about Hunt. Despite writing hundreds of pages for disability magazines, theoretical journals, and essay collections; Hunt's work was nearly entirely lost for decades after his death. Only two of his essays (**'A Critical Condition'** from 1966, and **'Settling Accounts with the Parasite People'** – published posthumously in 1981) were available – first through being quoted at length in articles by academics and journalists, and eventually by being digitised by the Centre for Disability Studies at the University of Leeds. Happily, this situation is beginning to change with more effort being made to archive and preserve the history of disability politics.

Early life

Paul Hunt was born on March the 9th 1937 to a lower-middle class family in Angmering, Sussex; he was the middle child of seven, and his parents' only son. At the age of five, Hunt and one of his sisters were diagnosed with Muscular Dystrophy (MD), a muscle wasting disorder that causes muscle weakness, fatigue, and mobility problems. Today, MD is understood as a range of neuromuscular conditions which effect the body in different ways; effective treatments have been developed for many kinds of MD, and people with them usually live long and active lives. In the 1940s, however, doctors knew much less and often assumed those with MD would die very young.

Hunt's parents, like many others at the time, did the best they could to make sure their children weren't left out of the world just because they had an impairment. Fearing Paul and his sister would get a second-rate education in special schools, the Hunts encouraged them to read widely, to write down their thoughts and ideas, and to get interested in music and the arts

through the radio. As pious Roman Catholics, the family also used their faith and church to give the children educational opportunities; and Hunt was introduced to philosophy, theology, and religious ethics early in his life. With no support from the state, however, it was impossible to keep both the children at home. Finding an appropriate wheelchair for Paul, and a house suitable for a wheelchair user, became major hurdles as he got older and his mobility decreased.

The family muddled along together during Paul's schooldays; he first went to an all-girls primary school run by the Church, which was more accessible than others nearby, then a mixed junior school, and eventually St Mary's boarding school for disabled children in Bexhill, where he could at least go home for the holidays. At the age of 14 he fell and broke his leg outside of his local church, after which he needed a wheelchair and couldn't manage in the family's inaccessible home. He was sent to Queen Mary's children's hospital Carshalton where he lived permanently and continued his education until the age of 16. Then, as now, circumstances changed as soon as disabled children became adults and lose any support they might get from the education system or children's charities. For Hunt, turning sixteen and finishing his exams meant being sent to what was called a 'chronic ward' at St John's Hospital in Battersea.

St John's was nothing like the hospitals in our cities and towns now – with their various departments where local people go to get cured of whatever happens to ail them. The hospital was dominated by mental health, geriatric, and chronic wards – places where no serious attempt was made to return patients to the outside world in better health than they came in. These long-stay wards were simply medical dumping grounds, where patients who couldn't be cured of whatever condition were thrown together in vast, crowded rooms. The nurses and doctors running the wards were often indifferent to the wishes and needs of those living there – 'chronic cases' were a career dead-end in medicine, and there was little incentive to do the job well. This added neglect, and sometimes even cruelty, to a

hospital set-up that was inherently traumatic for people living there. Many in the chronic wards were elderly or very ill, and went through the last moments of their lives in cramped dormitories without any privacy. With so many people, and so few staff, it was near impossible for patients to be treated as individuals with their own preferences, even in rare cases where workers did take an interest in their welfare. To live on a ward was to be surrounded by death, to be robbed of any individuality, and to lose any control you'd had over your life²⁰. Hunt fell into a deep despair, and years later found it difficult to talk even to his wife and closest friends about his time there.

Hunt's world: disability and social change in the 1960s

It would take a long time for chronic wards to disappear, but when Hunt moved to Battersea institutions like them were already under attack from more enlightened sections of British society. The end of the Second World War changed how health and social services were run; replacing a hodge-podge system of local charities running their own hospitals, asylums, and benefits schemes with one where central government provided health services and cash benefits. One consequence, however, was that nationalising welfare services made it obvious that public money was being used for dehumanising types of care²¹. With hospitals and (eventually) mental health services taken into public ownership, hangovers of the old system like the chronic wards seriously undermined promises of a bright future.

For twenty years after the war, public discontent focussed on the institutionalisation of older people and people with mental distress. 'Disability' wasn't even a word with any fixed meaning as far as the health and social services were concerned; and services and benefits had more to do with **how** someone got their impairment than with what the impairment was. There

wasn't really a language in which to describe disabled people as one group²², so it's not surprising that they were overlooked in press campaigns about the horrors of institutions or the government's responses to them.

There was, however, a real change for a few hundred disabled people who either lived in chronic wards or feared going into them. The government took over the hospitals and shut down the old welfare networks, but left a gap where the old system had offered a different kind of support to some impaired and older people – usually in large, segregated, residential homes. Some new charities were interested in filling that gap with experimental living arrangements and forms of support. They had a good pitch: the current system wasn't working and the government had no idea how to fix it, and the war had created rehabilitation techniques and aids for injured soldiers that simply weren't available to most people with similar conditions. By combining these techniques with different kinds of personal support in new care homes (usually referred to as 'Homes' with a capital 'H'), these new charities argued they could do what the government couldn't; provide places where disabled people's abilities were valued and encouraged, where they were treated like adults, and became part of a community. The pitch worked for Hunt, who saw a television program about a charity called The Leonard Cheshire Foundation for the Sick in the autumn of 1955. The group had a Home nearby, where residents had an unheard of amount of freedom, and it was led by a deeply religious war hero trying to change the way society thought about ill and disabled people. Hunt wrote a letter to the Home asking for a bed in one of its shared dormitories, and moved in the following summer.

The Leonard Cheshire Foundation

The Leonard Cheshire Foundation (usually referred to as 'The Foundation') was a uniquely liberal and empowering environment for residents in its early days, largely because it was badly planned and chaotic. Group Captain Leonard

Cheshire found himself in the care home game by accident. After finding fame as a wartime bomber-pilot, and participating in the nuclear bombing of Hiroshima at Winston Churchill's request, Cheshire dedicated his peacetime life to building more pure, moral and equitable ways for people to live together. His first venture was a commune for ex-servicemen, based at the rickety Le Court mansion he'd bought from a wealthy aunt. The commune, named **Vide in Pacem** ('Go in Peace' in Latin, 'VIP' for short), was immediately threatened by the complicated financial arrangements used to cover its initial costs. Neither Cheshire (who was notoriously bad at paperwork), nor other commune members had the skills to manage the debt and VIP quickly fell apart – although Cheshire managed to keep hold of Le Court itself.

One former VIP member, Arthur Dykes, later contracted terminal cancer, and the new National Health Service wasn't sure what to do with him. They contacted his last known address, Le Court, and Cheshire agreed to nurse Dykes himself. Due to Cheshire's fame and talent for self-promotion, he was soon getting requests for places at Le Court from hospital managers keen to free up beds, and patients equally desperate to escape hospital wards. Soon, he'd filled the bedrooms at Le Court, and set his sights on opening other Homes, run by a charity with his name on it²³.

Cheshire justified his charity with an anti-institutional philosophy. In place of the impersonal and stultifying wards, Cheshire's properties would be 'run as homes rather than hospitals (...) [and] offer the affection and freedom of family life, the patients being encouraged to take whatever part they can in the day-to-day running of the home'²⁴. Cheshire's fame attracted money and voluntary labour, but his ambition nearly always found a way to make the whole project precarious. As soon as one Home was opened and filled, Cheshire got going on another – first in England, then anywhere in the world he could get land. If he lacked the money, the labour, or even the buildings, Cheshire began anyway and hoped that something would turn up. Given his celebrity and aristocratic contacts, it

usually did. For those living and working in the Homes, however, he was something of a whirlwind; leaving abruptly after a Home had been established and leaving no instructions as to how the community should be run.

Without guidance from above, residents and staff at Le Court took Cheshire's philosophy at its word. The residents, they figured, were adults and had every right to decide how to spend their days and run their Home. Individually, residents had the right to get up when they wished, follow whatever interests they liked, and have the same vices as everyone else – afternoons in the pub, love affairs, entertainments and material comforts – should the fancy strike them. An elected Welfare Committee of residents met with the Warden and staff to decide the day-to-day running of the Home – including decisions around admissions, how staff did their jobs, and group activities like film showings or visits to shows. The Committee also had the right to decide how any donations should be spent. This democratic system soon knocked down social barriers between staff and residents, who began to see themselves as friends and neighbours rather than professional helpers and the helped²⁵.

It's no exaggeration to say that the Le Court Hunt moved into was a beacon of liberty for disabled people who otherwise faced grey, restricted, and impoverished lives. The crumbling old mansion had been replaced in 1954 with a modern, much more accessible building – largely funded by donations from bankers and industrialists who wanted to prove that private charity was superior to the welfare state²⁶. Disabled people in this community found themselves, for the first time, in a built environment that designed with their mobility and independence in mind. The social opportunities in Le Court were also dazzling for any young person, let alone one, like Hunt, who'd been locked away in a hospital ward. Not only did the Welfare Committee allow Hunt a position of responsibility that was unimaginable in a hospital; the whole environment was bristling with art and culture, and had a more exciting social life than most fashionable neighbourhoods. Cheshire's

fame attracted artists, writers, engineers, and other intellectuals to volunteer at the Home, and residents were keen to use their skills and networks to increase the richness of their own lives. Before long, some residents became respected novelists, film-makers, painters, and poets, using their well-connected 'slaves' (Le Court slang for volunteers) to promote their work in the wider world.

An in-house magazine, **The Cheshire Smile**, was set up by residents to encourage discussions and debates in the Foundation on whatever issues mattered to them most – whether theology, international relations, or the varying qualities of hair and beauty products. Hunt, who'd began devouring books of philosophy, sociology, and literature as soon as he left hospital, became heavily involved in the **Smile**, sitting on its committee and regularly publishing reviews of what he was reading – before eventually moving on to more substantial articles about his own ideas.

Cheshire and other leaders of the Foundation had an awkward relationship with these residents' achievements, and the liberal regime that underpinned them. On one hand, the Foundation needed empowered and outgoing residents to prove it really was different to the hospital system, that it could develop the skills and abilities of disabled people in a way the state had failed to. The residents were also just better at promoting the Foundation than anyone else, except Cheshire himself. Films made by Le Court residents were useful for fundraising, and the **Cheshire Smile** became the main way supporters kept in touch with the Foundation – partly because its quality and mixture of serious articles and humour made it a good read, partly because the Foundation's leadership were too disorganised to put together an 'official' newsletter.

There were, however, reasons to try and clip the residents' wings. Firstly, there was the question of authority. Cheshire's father had eventually convinced him that there must be some stable management for the Homes if the charity was to survive. Those at the top of the Foundation hand-picked respectable

citizens – often ex-military officers – living near each Home to act as its Management Committee; in charge of decisions around hiring, admissions, and supervising senior staff. Not only did this take power away from the Welfare Committee, replacing their say over their Home's daily routines with decisions by people who didn't live there, but the average manager was a social conservative and horrified by the liberal atmosphere at Le Court. Homes that were started with a Management Committee in place never had the kinds of freedoms that Le Court had, and Le Court's Managers did their damndest to stamp out the most obvious signs of residents' autonomy there. The more residents and staff resisted, the weaker managers' authority looked and, by extension, the weaker the authority of the man who'd given them power to run the Home – Leonard Cheshire²⁷.

More serious were attempts to sort out the Foundation's long-term finances. The Government had been toying with the idea of nationalising care homes since 1959²⁸, and in the mid-60s things looked threatening. Cheshire had never been good with money, and the Homes mostly survived on donations and per-bed payments from hospital managers for patients they had shifted on. Any push towards nationalisation threatened both types of income²⁹. In the end, the state dropped its plans, but Cheshire and the Foundation's leaders spent much of the '60s dreaming up new ways to protect their charity. They ultimately decided to become a sort of odd-job man for the health service; making themselves too useful to be taken over, and getting long-term funding for jobs that hospitals couldn't, or didn't want to, do. The Foundation launched several schemes in this vein, but what they all had in common was that they brought more aspects of hospital life into the Homes. The numbers living in each Home would go up, becoming more like the over-crowded and anonymous hospital wards. Staff would be forced to take orders from medical supervisors, rather than negotiating their workday with residents; and it stood to reason that health services managers would only sink serious money into something that abided by other medical rules.

Battles between residents, managers, and the Foundation's trustees over these issues started in earnest in 1960, and lasted the rest of the decade. Background information to the individual struggles by Le Court residents to protect their liberties are contained in the introductions to the first three sections of this volume, but the fact that there was conflict at all had a profound effect on Hunt. As a young and pious Catholic, Hunt believed that other people's free will was sacred, and hated the idea of forcing management to give in to residents' demands through confrontational tactics – even if managers would happily prevent the community from using its free will. He was also intensely loyal to Cheshire, whose work at Le Court and vision for the Homes had saved him from inhuman conditions in St John's Hospital.

He initially squared this circle by saying that the Foundation's lack of a clear purpose was its main problem. Cheshire was, he believed, a good man, but he and the Foundation had got distracted by building more Homes before they'd solved the problem of how people live together as equals. Building real communities for disabled people meant that residents must have the right to make their own decisions about life in the Homes, and Foundation leaders could be persuaded of that through discussion with residents. While confrontational tactics might be necessary in the short term to stop life at Le Court becoming unbearable, Hunt believed he could win the real argument by appealing to the beliefs everyone in the Foundation held in common³⁰. This informed his earliest writings in the **Smile**, where he looked at the most radical experiments in community building in Britain and argued that the Foundation must try and learn from them.

But as the decade went on, this position became harder to hold. The Foundation's leaders didn't get any clearer about what their charity was for, but it became much clearer where they stood on residents having any say over how it was run. Le Court's managers quickly became, to quote Hunt's diary, 'determined to destroy so much that is good here'; 'in the name of order' they laid off workers who took the residents'

side in disputes, and threatened to expel residents who objected too strongly to any new rules imposed on the Home³¹. Cheshire at first refused to get involved – although rumours that he or his father had approved, or maybe even suggested, managers' tactics were going around as early as 1962³². By the middle of the decade, he'd very clearly picked his side. When residents argued, in the **Smile**, for power-sharing between people who lived in the Homes and their managers, Cheshire attacked them through the magazine; accusing them of being selfish, power hungry, and ignorant of the wishes of their neighbours who were (supposedly) perfectly happy with how things were³³.

Clearly neither Cheshire nor his management were in the market to be persuaded. But Hunt still believed he could get the Foundation's residents, volunteers and supporters on side in large enough numbers that the leadership would have to negotiate. He got to work appealing to them in the **Smile**, and writing for whatever journal, magazine, or newspaper would publish him about the position of disabled people in institutions.

None of these strategies bore fruit, at least at the time. Occasionally, volunteers would write supportive letters to the **Smile**, but wouldn't or couldn't go any further. Residents elsewhere were often in an impossible situation. Like Hunt, the Foundation had given them a way out of unbearable conditions in hospitals or family homes where they had limited support. They were, understandably, either grateful for the comforts of even the most authoritarian Home, or frightened of expulsion to a chronic ward if they made too much noise.

Pressure from elsewhere also looked unlikely. The government quietly dropped its plans to nationalise the care charities; and became more interested in minor reforms than radical changes. Disabled people under 65 were eventually removed from older patients' wads, but the 'Young Chronic Sick Units' they were sent to were hardly better³⁴. Local councils were encouraged to build their own residential Homes when no others were

available, and there were loose guidelines from Government on how to staff institutions, but these reforms fell well short of what Le Court residents were arguing for³⁵. In a private letter to a close friend in 1967, Hunt was forced to concede that residents' freedoms might be impossible to save in the Foundation, that 'we may have got as far as we are ever going to here'. The realisation was clearly traumatic, and Hunt describes losing his faith in God in the same letter³⁶. Less than three years later, he'd leave Le Court for good.

Disability and politics

In the same letter from 1967, Hunt explained that he had become 'primarily concerned with politics in the widest sense - and principally, of course, in the world of the disabled'. For the first time since the 1920s, when the National League of the Blind and the trade union movement had won benefits and tax concessions for blind workers after a long agitation, there was an awareness of disability issues amongst politicians, the civil service, and the public at large.

In the early years of the welfare state, what we now think of as disability issues – access, integration, discrimination, etc. – were divided between different sets of rights for different groups. Occasionally, most notably for blind and deaf people, rights and entitlements were given simply because one had a particular impairment. More commonly, though, they were given because an impairment came about in a particular way. The state offered those impaired through accidents at work, or while serving in the armed forces, reasonable pensions, occupational therapy, mobility aids and retraining for different kinds of work. The government introduced laws to encourage employers to hire workers from these groups through a quota system – although opinion is divided on how effective this was. For everyone else with an impairment, however, there were no specific rights or entitlements at all. The obvious human impact was poverty and the breakdown of support networks. In the absence of help from the state, friends and families were

forced to reduce work hours to provide support. The whole family either lost income and suffered together, or put the disabled relative into a Home or hospital in order to survive. The political consequence was that there was no 'disability politics' as we understand it today – only blind politics, deaf politics, industrial politics, or the politics of the armed forces³⁷.

The first group to see a link between the human problems disabled people faced and the way the state understood disability was the Disablement Income Group (DIG) – a large campaigning organization started in 1965. DIG was mostly interested in the benefits system, and the fact that most disabled people (and particularly disabled women) faced exclusion from the welfare state. The first step to putting this right, they argued, was for the government to accept that disability was a 'category of being' covering everyone with an impairment or health condition – no matter what it was or how they got it. Once the government accepted this, DIG argued, they could not exclude what they called the 'general classes' or 'civilian disabled' from the same benefits and rights enjoyed by disabled ex-soldiers or workers with industrial illnesses³⁸. Hunt became an enthusiastic member and propagandist for the group, first in articles for the **Smile** and other publications³⁹, and later becoming active in the organization in London.

DIG was in many ways a frustrating group for its disabled members, and a more detailed discussion of Hunt's complicated relationship with it covered in the introduction to Section 5. There were, however, elements of DIG that had a profound effect on his work and thought. Firstly, DIG's leaders argued that not all the problems around institutions were about the people who lived in them or, in fact, the people running them. People ended up in hospitals or residential Homes because they had no other choice and, DIG argued, they had no choice because they had no money. A decent income would either allow disabled people to pay for help at Home, or give them power to bargain with institutions over how they were supported there⁴⁰. Many problems disabled people faced, then, were not inevitable, and were based in the way society was

organized and who had which resources. DIG argued that society should solve these problems at their root, the problem of poverty, and let disabled people work out the rest for themselves. Hunt would come to argue that more money in people's pockets doesn't magically solve the problems DIG pointed to, but that core argument about where disability issues come from would be crucial to his later work in UPIAS.

DIG also raised the question of disabled people's control over disability campaigns and organizations – although they were unable to solve it. The average disability organization would have few, if any, disabled people in its leadership. This was, to some degree, a legal requirement. The National Assistance Act (1948) had tackled corruption in charities by making it illegal for their leaders to benefit from the organization's activities. A lot of campaigning groups registered as charities to avoid massive tax bills, and the result was that old ways of working, where non-disabled people made decisions on disabled people's behalf, continued unchallenged.

DIG found a legal loophole for this problem: separating the charity that held the money from the group that did the campaigning for the purposes of its paperwork⁴¹. They created an open membership system where anyone could join, vote on policy, and be elected to leadership regardless of whether they had an impairment. This was revolutionary at the time, and disabled people joined in large numbers. Disabled women in particular, who were the most disadvantaged by the welfare system, were almost always present in DIG's leadership.

Despite this positive development, open membership exposed new problems. Disabled people were always a minority in DIG – albeit a large one. DIG also attracted numerous non-disabled professionals – politicians, medics, academics, and people from other charities or anti-poverty campaigns. These people often had set ideas about how social change happens; it involves working with, not against, those who hold power, and it takes a very long time. This caused tensions with disabled members including Hunt. Disabled people were living with problems

caused by society now, and needed things to change now – even if that meant taking shots at important people. On questions of strategy, who should have the greater say? The people who had to put up with what everyone agreed was appalling discrimination and poverty, or those who didn't but happened to have more votes? These questions eventually led to a split in the mid-70s, but not before a lot of anger and recrimination on all sides⁴².

Disability and the academy: jockeying for position

The push against institutions in the early '60s, and the activism of DIG, were tied up with intellectual trends of the time. Academics were on the leaderships of both the Cheshire Foundation and DIG, and their ideas influenced younger professionals through training courses and journals. As critics of society by trade, intellectuals were great at pointing out the injustices of disabled people's treatment. DIG, in particular, used academic papers to design its propaganda and sharpen its policy and strategy. There was the added benefit of academics' social influence – professors at elite universities and disabled people in hospitals often said similar things about the benefits system or the harms of institutions, but professors were much harder for polite, newspaper reading society to ignore.

There were, broadly speaking, two new strands of academic work and research concerning disability. The first was straightforwardly technical and based around rehabilitation. It looked at medical and non-medical treatments which restored physical functioning, and ways of adapting built environments for people with different conditions. The other strand came from the social sciences and psychology, and asked **why** people with certain physical or mental conditions ended up in such an unequal position in the first place, and what role segregation, long-stay hospitals, and care homes played in society more generally. Towards the beginning of the 1960s, both offered disabled people in general – and the avid reader Hunt in particular – exciting new ways to think about disabled people's place in the world. By the start of the next decade,

however, there were real reasons for Hunt to suspect academics' commitment to disabled people's autonomy.

Both the war and the explosion of new technologies afterwards created new resources and treatments to deal with various bodily conditions. Medics and designers came up with new ways of minimizing the impairments of injured soldiers – including treatments to restore the use of limbs, aids to replace lost organs, and new designs for wheelchairs and cars for people with very limited mobility. This was complemented by adaptations made to workplaces during the war to get disabled workers into industry – as one of the previously excluded groups (alongside women and black people) now expected to cover shifts for the men sent off to fight. Slightly later, the computing power that revolutionized British industry was shown to also be useful for disabled people. Before long the Patient Operated Selector Mechanism (Possum) – a primitive computer that could be operated by mouth – allowed richer disabled people to operate typewriters, telephones, TVs and doors without having to leave their beds or chairs. Soon, an international discussion was underway between medical researchers, architects, computer programmers, and designers over how to bring all this knowledge and technology together. This question spurred several scholarly journals, international conferences, and generous research grants for academics.

Hunt would only really get to know these debates well in the 1970s, around the same time as UPIAS was founded. Rehabilitation journals were short-run academic publications – hard to get hold of, and even harder to read. During the '60s, he was most familiar with attempts to popularize rehabilitation science by experts trying to influence society more directly. The most important of these, for Hunt, came from probably the two most radical people working in the field: Dr. Margaret Agerholm, a rehabilitation specialist and trustee of the Cheshire Foundation; and Selwyn Goldsmith, a disabled architect with a knack for explaining complex ideas in a readable style.

Where most of their colleagues saw disability as a personal tragedy, which it was the professional's job to treat using knowledge provided by academics; Agerholm and Goldsmith dissented from this cure-or-care model. Agerholm argued forcefully that disabled people knew what worked for them better than anyone else did, and that rehabilitation needed their knowledge just as much as expert research and technology⁴³. In a similar vein, Goldsmith thought it was all well and good to look for new therapies, or point out the ways that buildings or transport could be designed differently; but the underlying problem was that society assumed that disabled people should not use various kinds of public space. This, he claimed, was because society as a whole made misguided assumptions about how disabled people thought about themselves and the world – that being in certain kinds of public situations would be upsetting to them, that they felt so much shame that social interactions were unbearable, etc.⁴⁴. Goldsmith set out to counter these myths, putting long essays on the 'psychology of disability' into his otherwise technical books on architecture, and picking fights in newspaper articles with anyone who disagreed with him.

Goldsmith and Agerholm wanted to add social and psychological insights onto medical ways of thinking about disability, but the second strand of academia wanted to get rid of the idea that disability was a medical problem in the first place. The Canadian sociologist Erving Goffman opened this line of argument with his analysis of stigma and the 'medical model' of dealing with it. Disabled, older, and distressed people, he argued, were unsettling to a society which valued strength, beauty, and financial independence. Unlike other groups society found upsetting – criminals, Jews, black people, and gay people – it wasn't so easy to stick them in ghettos or prisons and hope they never got out. Instead, society came around to a great myth; that these people had special medical needs, and that hospitals (or things very like them) were the only places those needs could be met. In taking this step, society changed hospitals from being something like a repair

shop (where people go to get their body fixed) to something like a prison – warehousing the people society doesn't want to see⁴⁵. Soon, a slew of sociological and psychological studies explored how disabled people responded to being pushed out by society; how did it effect their sense of self?; their behaviour?; their relationships with other people?

At the beginning of the '60s, this development was viewed positively by Hunt and many of his neighbours at Le Court. They were prepared to accept academics' claims that they had some psychological hang-ups because of their situation, if researchers were serious about combatting the oppressive ways institutions were run. Le Court residents arranged for two researchers – Eric Miller and Geraldine Glynne – to spend time at Le Court and study the power relationships between staff and residents, hoping their findings would convince management that making the Homes more like hospitals would do more harm than good.

That wasn't how things turned out. When Miller and Gwynne finally published their findings in a book called **A Life Apart**⁴⁶, they were incredibly insulting to the people who had invited them into Le Court. Miller and Gwynne agreed with Goffman that mainstream society rejected disabled people, but broke from him by claiming that this was wholly justified. Disabled people, in their eyes, were 'parasites' leaching off the work and energies of the able-bodied, and it was a sign of society's enlightened values that it bothered housing them at all. Institutions, they argued, bridge the gap between someone's rejection by society, or their 'social death', and their actual death; a job which would include conflicts no matter how anyone tried to organize it. As such, Miller and Gwynne were not concerned with untangling the knots of actual disputes between people living and working in the Homes. They were very interested, however, in proving that everything that happens in institutions can be explained by 'open systems theory' – a niche sociological theory which Miller had invented.

Residents were angry, and felt they had been betrayed. Hunt began by trying to beat Miller and Gwynne at their own game, writing a review of the book in the **Smile** that pointed out that their arguments contained gaping holes, that they'd misapplied other scholars' ideas, and that they'd drawn sweeping conclusions after spending very little time in only a handful of Homes and hospitals⁴⁷.

As the book became more influential, Hunt began to suspect there was more than just bad scholarship and bigotry at play. **A Life Apart** had few useful conclusions for anyone working or living with disabled people; but this hadn't prevented it being placed on university reading lists, or Miller being offered lucrative government work off its back. Other academics working in disability could also point to few practical results, but appeared to have done personally quite well out of their involvement with disability. Agerholm, despite failing to get the Cheshire Foundation to adopt any of her ideas, was a nationally and internationally respected expert on disabled people and their needs. She used this authority to come up with her own definition of disability, and to tell the government what services they should be running according to it⁴⁸. This rather clashed, to put it gently, with her earlier belief that disabled people should decide such things for themselves. Academics involved with DIG, likewise, had benefited from regular meetings with government which often resulted in grants for research into disabled people's poverty; while in the organization they tended to be one of the more conservative elements. Disability was, it seemed, a way to open doors and improve your career if you were an intellectual; whether you turned out anything useful to disabled people was a secondary concern at best.

Once something (like disability) is recognised as a social problem, Hunt noticed, there are career opportunities for intellectuals and academics willing to justify the status quo or, if change is unavoidable, to advise those in power how best to manage it. Since the end of the war, the section of intellectuals exploiting these opportunities in relation to disability had been the rehabilitation scientists; who had worked closely with

governments, private industry, and charities. Hunt now saw the explosion in sociological and psychological work on disability as less about shaking up oppressive systems, and more an attempt to shake the rehabilitation scientists out of their dominant position. Studies like Miller and Gwynne's didn't really try to find better ways for disabled and non-disabled people to live together; they attempted to carve out a slice of the disability problem for sociologists, rather than anyone else, to be experts on.

This meant that neither camp of scholars were interested in objective research on disability – no matter how often they claimed to only deal with facts. Researchers were, first and foremost, interested in their careers and, secondly, with promoting their academic disciplines in a competitive marketplace of ideas. Any promising ideas from the early-60s were easily traded away, as scholars like Agerholm dropped their sharper criticisms of society and medicine when offered positions of influence. The real losers from this were disabled people. Not only was their situation used as a launch pad for academic fads, but their voices and ideas got lost amongst the chatter of so-called experts. Any demand by disabled people for dignity, freedom and control over their own lives could be, and often was, rejected as incompatible with the most cutting-edge research. For Hunt, it didn't matter whether it was medics or sociologists throwing disabled people under the bus in this way; the result was basically the same⁴⁹.

The decline and rebirth of disability activism

By the early 1970s, all the progressive causes Hunt had supported the previous decade had become dead-ends. The Cheshire Foundation had continued drift further from its anti-institutional roots – with strict hierarchies in the organisation, medical professionals in the Homes, and a much more conservative editorial line in the **Smile**. DIG had failed to cope

with the 1970 election of a Conservative Government which was less interested in paying lip-service to poverty issues than their Labour predecessors. DIG's leadership was so out of ideas they suggested dropping the demand for a universal income for all disabled people, and replacing it with something less radical that a right-wing Government might accept. In fact, even this looked unlikely after the economic crisis of 1973, when it became clear that welfare spending on disadvantaged groups wasn't going to increase any time soon.

There was a lot to be disillusioned with, but ironically it all came at a time when Hunt himself had more personal freedom than at any time before in his life. Hunt had left Le Court in 1970, and married Judy – a former worker from the Home. Judy was an intellectual stimulus for Paul, as well as being his life partner, and the two would discuss ideas at length. They explored Marxism together, debated what was going wrong in the movements they were part of, and made comparisons between the social position of disabled people and the oppression of women and black people. Hunt had attended an adult training course in computer programming, and later found work as a programmer for Remploy – the government agency that ran adapted, if segregated, workshops and factories for disabled workers. Through this work, Hunt became intimately more aware of how technology could be used to give greater freedom to even those with the most complex impairments. The combination of a home outside an institution and a job to support himself meant that Hunt was now free to say whatever he wanted to – without fear of expulsion or victimisation by staff or management.

Hunt also had influence amongst many disabled people, alongside something of a public platform. Hunt's qualities as an organiser in the Le Court struggles were well known to rebels in residential Homes around the country, who saw him as a natural leader of their fight against authoritarianism. He'd also built a reputation as a serious thinker through his writings in the **Smile**, and used the network of intellectuals around the Foundation to get his analysis out in other media – no mean

feat for someone who'd never been to university, and who'd relied on local libraries, volunteers' bookshelves, the **Cheshire Smile's** post box, and the odd begging letter to publishers to feed his voracious appetite for books and journals. In addition to publications in the **Guardian** newspaper and Catholic journals, a publishing house loosely connected to the Foundation had commissioned him to edit a book of essays by disabled people. Published in 1966, **Stigma**⁵⁰ was the first collection to lay out disabled people's experience of exclusion and oppression in their own words – relying heavily on personal accounts by eloquent disabled people in or around the Cheshire Foundation like Louis Battye and Audrey Shephard.

Hunt's own essay in the book, **A Critical Condition**, showed off his talents as a writer and thinker. It expanded Goffman's claim that disabled people's treatment came from society's irrational response to physical difference, and was connected to discrimination against racialised groups. The difference between disabled and non-disabled people, Hunt argued, was deeper than Goffman had given it credit for. Disabled people were not just unlike the 'able bodied'; they challenged the whole value-system of non-disabled society. Society was, for Hunt, a competition for money and status. Where physical fitness and the ability to earn a living were held up as the essence of being human; disabled people reminded it that the human condition is essentially frail and dependent. Society chased after fleeting pleasures, usually tied up in consuming commodities; but the fact of disability shows that pain and death are inevitable and linger over every human life. Just by being who they were, disabled people were a challenge to society's ideas about itself, and their social acceptance therefore meant society coming to terms with a more enlightened understanding of what it means to be human. Hunt would later disown this argument, and it fits very badly with his other writings at the time (which stress what disabled people have in common with everyone else, rather than their differences), but it was popular for decades afterwards. Here, for the first time, was an attempt to define what disability

meant for society, using a theoretical framework that intellectuals held in high esteem. Journalists, sociologists, and social policy scholars regularly quoted it in their work, and recommended it to their colleagues.

Hunt would use this influence to form UPIAS, acting as its primary organiser and one of its theoretical powerhouses for the rest of his life. UPIAS was part of a larger re-birth of disability activism after the failures of the 1960s. Hunt saw, more clearly than many of his peers, the radical implications of trying to go beyond professionally dominated campaigns and organisations; but his contribution should be understood alongside that of other disabled people, inside and outside of UPIAS, who'd also realised that something was deeply wrong and that new ways of working were needed.

Things fall apart: the end of the disability consensus

The Cheshire Foundation and DIG were not the only campaigning disability organisation to give up on their radical roots. Across the reforming organisations of the '50s and '60s, there was a breakdown in the fragile alliance between disabled people seeking new ways to live and those who now held the power and resources which could make change happen. The Spastics⁵¹ Society, for example, was a residential charity for young people with Cerebral Palsy, and had started with a similar anti-institutional attitude to the Cheshire Foundation. Instead of locking people away in hospitals, they argued, young disabled people needed to be given a chance to control their own lives and integrate into mainstream society. Like the Cheshire Foundation, they too became less keen on this idea when residents used it to demand a greater say on how the Society was run, leaving a frosty stand-off between residents and staff in Society hostels and day-centres⁵².

There were also once promising, but now burned out, projects by disabled people and sympathisers in the Labour Party to change its policy on chronic wards. A small group of

Party members launched the National Campaign for the Young Chronic Sick to demand wards' closure and replacement by support to live in the community. The National Campaign was tiny, but it had significant support from the trade union movement and ordinary Party members. Then there were Labour Members of Parliament (MPs) themselves. Often drawn from working class communities, Labour MPs of the 1960s were likelier to be interested in the difficulties of being disabled in a poor area, and how they fell through the gaps in the welfare state, than politicians of previous generations⁵³.

Despite these pressures, disablement was not a high priority for either the Prime Minister Harold Wilson or the rest of his Cabinet. It was, however, impossible to ignore it entirely. The messy compromise reached was the Chronically Sick and Disabled People's Act in 1970. It was drafted by Alf Morris, the Labour MP for Wythenshawe in Manchester, with help from members of DIG and the National Campaign. It contained a list of community services that local councils should provide for disabled people, as well as their right to be consulted on what further support should be offered. At first, Wilson's government objected that this was too expensive, but eventually let the Bill pass after removing sections that made central government pay for new services. Without funding, however, local councils couldn't put the measures Morris wanted in place, and the Act was never seriously enforced⁵⁴. While Hunt was not directly involved in the Labour Party and trade union agitations for the Act, he was well aware of the anger many disabled people felt at being let down by the Government. Letters from people fuming about the Act's toothlessness streamed in as soon as UPIAS was founded in 1972, and its members around the country were still unable to make councils consult on new services in the 1980s⁵⁵.

Disabled People's self-organisation

There was clearly a lot of anger and disillusionment to go around. Some disabled people stayed in the campaigns and

organisations they were in, hoping to either improve them from the inside or that eventually their leaders would break through the various deadlocks. Others, however, looked to a different way of organising to protect and expand their own interests. Some disabled people had been controlling their own small organisations since the end of the 19th century, with a slight growth in self-organised groups immediately after the war. These had largely limited their interests to single issues, and their membership to groups with one kind of impairment. As the need to break free of professionals increased, there was a growth of these kinds of organisations and a widening of the social issues they engaged in.

In 1968, the National League of the Blind opened its membership to all disabled people working in segregated workshops; trying, in one stroke, to organise all segregated settings into one big union. In the same year, rank and file members of the Disabled Drivers Association argued that the organisation should overcome its narrow focus on motoring and transport. Successful transport for disabled people, they argued, depended as much on having somewhere accessible you could go – workplaces, public buildings, entertainment venues, etc – and adequate support to control your life as it did the quality or availability of vehicles. These issues affected disabled people as citizens, not just as motorists; and the DDA must recognise this in its campaign strategies⁵⁶. A few years later, fed up with being overruled and hampered by the back-room politics of the blind charities, the National Federation of the Blind – a single impairment but multi-issue campaigning group – proposed cutting off all collaboration with charities not controlled by blind people⁵⁷.

At the same time disabled people who were not yet organised became frustrated with the quality of rehabilitation, medical, and charity services. While rehabilitation had become successful by promising freer lives for patients, power over what kinds of rehabilitation were offered and how people accessed them was almost entirely held in the hands of medics and occupational therapists. For people in rehabilitation (and

perhaps even more for those in the mental health system), it often felt like they were guinea pigs for the grand theories of medical scientists; forced to undergo meaningless treatments and therapies that had little to do with their real lives, preferences, or visions for their future. Disabled people reliant on the charities and local councils experienced similar exclusions from decisions about the support they received, although often without even the flimsiest of justifications. Charities and councils simply offered whatever services they thought people should have, and there was no obvious way for users to challenge poor quality or inappropriate ways of running them.

They realised that they had to take matters into their own hands. Organisations like the Brittle Bones Society, the Spinal Injuries Association, the Multiple-Sclerosis Action Group, and the Union of Mental Patients were formed across the country. Members were able to exchange information about which treatments worked and which didn't; and created ways of supporting each other beyond the control of professionals. This process allowed users and survivors to identify problems and solutions together, and form a united voice to challenge injustices in the system.

Hunt had supported self-organisation since the late '60s when he'd come across the Disabled Drivers Association, and was enthusiastic about the idea of 'militant' organisations taking on the vested interests which dominated the reform movements. In the next few years, the idea of disabled people controlling their own organisations became more important to how he thought about the failures of the '60s. He'd originally thought of self-organised groups as a way to keep other disability organisations honest – much like trade unions stopped companies underpaying workers, or consumer groups prevented shops ripping off customers. The idea was fairly simple. A self-organised group would support other disability campaigns and charities on issues that mattered to its members; but if they didn't act in disabled people's best interest, the group could show that they no longer had the

support from the people they claimed to care about. Strong organisations **of**, rather than **for**, disabled people would be a way of steering existing disability organisations in a more radical direction – rather than something radically different to, or separated from, them⁵⁸.

Two things made him think more deeply about the idea. The first was how powerless the reforming charities and campaigns had become in the face of the systems they'd tried to change. If the Cheshire Foundation and the Spastics Society now depended on the medical and social care systems they'd been set up to oppose, and if DIG changed its demands whenever the Prime Minister changed, was there still a disability movement worth trying to influence? The second was the failure of disabled people in these movements to come up with strategies for radical change. Hunt had previously criticised the leaders of the Cheshire Foundation for being unclear about what they were doing and why, but had disabled people involved in the Foundation, DIG, or any other disability organisation been any more strategic? In Hunt's view, he and other disabled activists had been too reactive; they saw very clearly that their lives were being made miserable, they knew that something needed to be done quickly, and they'd jumped into coalitions with non-disabled people who promised them change without properly assessing where these coalitions might go or their power within them. When radical promises got dropped, the best Hunt and his peers could do was to try to defend their earlier achievements – the freedoms at Le Court, DIG's original incomes policy, etc – against allies who now wanted to get rid of them. Disabled activists were left with no vision for change outside these alliances, and often no explanation of their situation that hadn't come from the people they were now fighting. It was no wonder they kept losing battles⁵⁹.

Disabled people controlling their own campaigns and organisations offered a way out. Not only would they allow disabled people to be as militant as they needed to be; disabled activists organising under their own steam was an

opportunity to discuss what was actually happening – why they were excluded from society, and what needed to happen for them to get freedom and equality. The problem with the old movement, as Hunt saw it now, wasn't just that non-disabled professionals controlled the charities and campaigns; they'd also controlled the ideas that disabled people had about their place in society. DIG had made all problems around disability a question of money, academics had made them a question of technology or of psychology, and the Cheshire Foundation had turned social questions about exclusion into questions about how to run residential Homes. There had been no opportunity for disabled people themselves to work out what was happening to them on their own terms or get at the root of the problems they faced. The reverse side of the coin, however, was that if disabled people didn't have these difficult conversations, they were doomed to jump from alliance to alliance with people who were, at best, only half committed to changing their unequal position. What was needed, Hunt believed, was not just an organisation that could do what the charities had failed to do, but one that could figure out what needed to be done and how⁶⁰.

Enter UPIAS

Hunt wasn't alone in coming to this conclusion. He and Judy had met Liz and Vic Finkelstein in 1971 at a conference of the Association of Disabled Professionals – a offshoot of DIG that brought together disabled workers to discuss discrimination in employment. The Finkelstein's had a profound effect on Paul and Judy's ideas about disability. Liz worked in schools for disabled children, and argued that the segregated school systems had no clear purpose. Not only could disabled children be educated in mainstream schools with the right adaptations to buildings and how subjects were taught, but the 'special schools' didn't really know what they were teaching the children **for**. Most teachers presumed the kids wouldn't end up in anything but the most meaningless work, and that they'd not

be able to take part in community life - so the children weren't taught any professional or social skills.. The special schools ended up as senseless hubs of pointless activity; they were set up whenever an education authority had enough disabled children in its area to fill one, but the children were often worse off simply by being sent there. In many ways, this argument was similar to Hunt's critique of Cheshire Homes in the mid-60s; but the fact that the education system was also separating out children for no good reason showed that the whole of society was deeply confused about what to do with disabled people.

Vic Finkelstein, Liz's husband, brought a new perspective to Hunt's thought entirely. A South African refugee who had only recently arrived in Britain, he had worked closely with the African National Congress and the South African Communist Party in their struggle against the segregation ('Apartheid') of black people. He'd been arrested for helping the Communist Party's leader hide from the police, and had been thrown in prison and tortured for his troubles. Marxism was something Hunt had been interested in as a philosophy since the mid-60s, but for Finkelstein it had been at the centre of a revolutionary movement to overthrow an oppressive state. In their early conversations and correspondence, Finkelstein stressed that whenever you looked at a question of oppression or discrimination, you could only understand it by looking outside of the thoughts, feelings and actions of the people directly involved in it. What had kept black people down was a social and economic set-up designed to keep their wages low and take land and resources away from them for the benefit of white capitalists. This had encouraged white citizens to discriminate against black people, and had made black people vulnerable to the petty cruelties of any white who wanted to make their life even harder; but it was the economic, political and social systems of South Africa that made black people unequal, not this or that racist white. If you were going to treat inequality and discrimination against disabled people seriously, Finkelstein urged, you had to look at what role that inequality

played in society – particularly in the economy and the class system of the country you lived in. Only by doing that would you have a clear idea of what you were fighting against, and be able to come up with strategies for changing your situation⁶¹.

So when Hunt decided to recruit people to a new organisation, he was convinced that it had to do more than just represent the views of disabled people as things stood. To prevent the mistakes of the '60s, this new group would have to sharpen up its ideas about why society treated disabled people in the way it did, why charities and campaigns kept letting disabled people down, and who benefitted from things staying as they were. These were tough conversations; carried out in a private journal and marked by disagreements and polemical articles between members. Bit by bit, though, the organisation which became UPIAS built up its own analysis of British society and its own theory of disability. Later known as the 'social definition of disability', it would transform the way disablement was understood in Britain and around the world.

Hunt did not come up with this theory himself – it was the result of two years of debate between around fifty disabled activists – but he was one of the leading voices in the discussion and one of the few people that members trusted to draft their ideas into the Union's key documents – its **Aims and Policies**, and **Fundamental Principles of Disability**. Their argument started at the core of capitalist society; workers competing for jobs, and bosses reaping the rewards. To make profit, bosses were forced to constantly change the way their employees worked – bringing in new technology, making workers work faster, and bringing in ever more complex management techniques to get an edge over other firms. People with certain kinds of bodily difference could not adapt to these constant changes. They either ended up completely unemployed or living a precarious existence jumping between low-paid jobs.

Exclusion from work didn't just mean exclusion from a wage. Cities and towns were built around workplaces; and, from

houses to busses to government buildings, the whole man-made landscape was designed to make sure workers turned up on time and ready to put in a shift. Consumer goods, too, were designed to be bought by workers with their wages. Because people with impairments were thrust out of employment, none of these things were designed with them in mind. Physically impaired people found themselves in a world built for bodies which weren't theirs; unable to navigate a hostile physical environment, and without the means to support themselves. In this condition, they became more dependent on their immediate family or friends, who in turn often found it harder to support them. A disabled person in your house often meant an extra mouth to feed out of everyone else's pay, and it could also be a threat to your own job. The more inaccessible the world, the more likely it was that those around an impaired person would have to drop their workhours or quit their jobs to support them with their most basic human needs.

This meant two things. Firstly what a disabled person's body is like does not cause the situation they find themselves in. Human bodies and minds differ from one another naturally, but it was the nature of work and the society built around it which had made bodily differences grounds for inequality. Borrowing, and subverting, language the government had recently used in surveys of disabled people; UPIAS distinguished between a person's impairment – a fact about their body or mind such as a missing leg, a spinal injury, or a neurological condition – and the disability thrust on them by the way society is organised. Secondly, it meant that disability was a problem for society – even though society had created it in the first place. What should society do with people it had made, to use Miller and Gwynne's terms, 'socially dead'? The usual strategy had been give some, usually pitifully small, income to disabled people and their families to prevent starvation and, when family support fell apart, to arrange for disabled people to be warehoused in hospitals or segregated homes. This created a market for segregated services; in which charities, professionals, and private companies competed for funding and

influence from the state. These groups were hostile to one another, and often happy to point out the horrors that each other thrust upon their disabled residents, but they were all committed to keeping the segregated system going. It was their bread and butter, and their careers depended on it. The only way for disabled people to combat their influence was to take control of all decisions made about their lives, and of the planning and running of disability services.

Sadly, Hunt died before these ideas captured the imagination of disabled people in Britain, but by the middle of the 1980s the distinction between impairment and disability was so influential that nearly everyone who thought of themselves as a disabled activist in Britain used its language. The 'social model', as the definition came to be known, was inspiring because it showed that disabled people's oppression was man-made and could be changed if society was organised differently. For UPIAS at the end of the '70s, however, the social definition raised as many questions as it did answers. How could they apply their theory when the majority of disability campaigns were still dominated by professionals, and most disabled people weren't sympathetic to radical ideas?; What balance should be struck between supporting campaigns which would improve disabled people's lives and attacking people in them who supported segregation?; If disablement was caused by capitalism, could disabled people's inequality ever really be solved within a capitalist society – or, put another way, would UPIAS and other disabled people's organisations have to become an openly revolutionary and socialist movement?

Hunt tended to be hard-line on these questions. If disability was caused by society, the point of self-organisation was to understand and carry out radical social change – not to negotiate a better deal within an exclusionary world. This required being up-front about what you believed and trying to win other disabled people around to your view – even if this made your life difficult in campaigns on the ground. It also meant you had to be very careful about who you worked with and on what; charities and professionals had a track record of

leading disabled activists up blind alleys which only benefited them, and the Union should only collaborate with them where they were prepared to give up power to disabled people on the ground. It was fine to work with a traditional charity on, say, a housing campaign which gave disabled people a say about where they will live; but not acceptable to take part in any movement where disabled people were left out of key decisions⁶².

Hunt's position was always less flexible than some members' of UPIAS, who argued that disabled people getting involved in collective action and challenging people with power in the first place was more important than how they did it. But his views only really became contentious towards the end of the '70s. UPIAS was in freefall; members were aware that their theory of disability was not well developed, and their work in local campaigns had less and less to do with what the Union was doing. They felt burnt out and directionless, and it wasn't clear to many that the Union had any plan which could turn the situation around.

Hunt saw the root cause of the crisis in a failure of the Union's theory. UPIAS had not been explicit enough in saying that capitalism caused disability and only socialism could resolve it. Only a thorough understanding of modern capitalism and a deep commitment to overthrowing it could give disabled people the knowledge and strategies they'd need to change a disabling society. This had been impossible to put into UPIAS's policy; most of the membership were critical of existing society, but they were not prepared to be in an organisation that supported revolution. As a result, Hunt believed, the social definition had been vague and muddled from the get-go. It had pointed out, correctly, that society excludes people with impairments and stops them controlling their lives; but it had been unable to say much about that society that wasn't far too abstract to be practically useful.

Hunt's solution was to disband UPIAS and replace it with a theoretical journal, in which a socialist analysis of disability

could be worked out and influence a wider pool of disabled readers. Interestingly, Hunt received his strongest opposition from a fellow Marxist: Vic Finkelstein. Finkelstein was just as revolutionary as Hunt, but stressed that an organisation like UPIAS was needed to build a disabled people's movement, and that thinking about theory was no good unless you were constantly applying it in campaigns to see if it worked. The discussion between the two became heated, and Hunt's side of the argument makes up the final section of this book. Tragically, Hunt died suddenly just as he and Finkelstein had started to agree a way forward together in the Union. UPIAS would recover from its crisis, and help kick-start a mass movement of disabled people in the early- and mid-1980s. It is one of life's cruelties that it's founder would not be around to see that movement.

Reading Paul Hunt Today

Hunt's early death, and the fact that his writings were out of print for so long, has led to a lot of confusing and inaccurate accounts of what he said and what he believed – particularly in academia. At best, historians and disability theorists have known that Hunt was important as an activist and a thinker, and have tried to piece together a picture of his thought as best they can. At worst, people have read their own beliefs into those of Hunt's writings which were available; sometimes even turning him against his UPIAS comrades. What's interesting in Hunt's work, for them, is that he can be read and quoted in such a way that their own ideas are given the authority of the disabled people's movement's founding father.

Partly to blame is the fact that the essays by Hunt which have been available for some time – barring the parts of UPIAS's **Aims and Policies** and **Fundamental Principles of Disability** that he wrote – have been quite unlike any other

parts of his work. In the case of '**Settling Accounts with the Parasite People**' – Hunt's only text dealing with how academics research disabled people – the effects have been harmless enough. Hunt's article was taken up by disability theorists like Mike Oliver and Gerry Zarb and turned into a critique of the dominant research methods used in sociology in the 1990s – when scholars were forced to choose between methods which looked at how people understood their personal experience, or 'objective' research that measured things in numbers. It's questionable how much Hunt would recognise of his argument when it was separated from UPIAS's theory of professional domination and forced into a very specialised academic debate, and it's even more debateable whether he'd agree with Mike Oliver that social research must offer disabled people 'empowerment through self-understanding'⁶³. The conclusion that Oliver and his colleagues reach, that disabled people must have more control over research about them, is, however, in line with Hunt's politics. What has been more damaging to our understanding of Hunt's work has been the taking up of an earlier essay as if it reflected Hunt's mature views and theory of disability.

'**A Critical Condition**' from 1966 started from the idea that disabled people were inherently different from everyone else, and that this difference appalled non-disabled people so much that they oppress them and lock them away. The fact that the essay laid out so clearly the emotional impact of discrimination, and that Hunt was unable to show any way for disabled people to break through society's hatred of difference, has made it a favourite of academic and other commentators across the decades. For the liberal journalist Ann Shearer, it showed that disabled people's inequality was caused by the values of non-disabled society; if we all empathise more with each other, we can make the problem go away⁶⁴. For the disability studies theorist Dan Goodly, the essay is 'a piece of critical psychoanalytic analysis' which is carried out 'in true post-structuralist style'; presenting the disabled person as a foil for modern societies who, just by existing, forces us all to confront

ourselves with our most painful fears and desires⁶⁵. For Goodley's disability studies colleague, Gareth Williams, the essay implies that there is tension between Hunt's thought and the social definition put forward by UPIAS. While the social definition makes disability a problem of society, not individuals; Hunt is read as saying that physical pain and feelings of sadness and anger – the most personal of all individual experiences – are a central part of what it means to be disabled⁶⁶. The fact that the social definition was put forward in documents largely written by Hunt, conveniently enough, is not mentioned.

Whether or not there is any merit in awareness raising campaigns by journalists, or psychoanalytic and post-modern theory, they have little to do with Hunt. '**A Critical Condition**' was one attempt to think through disabled people's oppression after the defeat of the residents' struggles in Le Court, before DIG had opened up a way (no matter how flawed) for thinking this through politically and economically, and during a period when it seems Hunt was struggling with his religious faith. Hunt drops the idea that disabled people are profoundly different creatures to the non-disabled almost immediately. The question, for him, is not how people feel about those who aren't like them; it is how to solve the 'essentially human problems' caused by separating people from one another as a matter of course. Both before and after '**A Critical Condition**', when he was a pious Catholic and when he was a committed Marxist, Hunt insisted that the real issue is that society treats people with impairments differently; not that they are different in any important way. Williams is right that there is a contradiction between Hunt's ideas in 1966 and what he thought a decade later, but the most sensible explanation is that Hunt abandoned an argument he saw was heading nowhere; not that he quietly held the views of a 21st century academic for the whole of his life.

If we are to read Hunt fruitfully today, we must accept that he is not speaking directly to us, and that he never felt like he'd finished his work. The years in which Hunt was writing were a

time when disabled people were figuring out for the first time that they shared a social situation, and were beginning to ask how to get equality with everyone else. Hunt was trying to make sense of what was going on around him in real time; and his early writings in particular are the thoughts of a brilliant young man about the world he found himself in – not a collection of timeless insights into the nature of disability. Even in UPIAS, where the mature Hunt and his comrades finally cut through the half-baked ideas and assumptions that had dominated disability campaigns until then; he knew that they had made a start, not a finish. The social definition gave a broad framework for understanding disability: but it needed to be deepened through thought and action before it could answer all the problems of disabled people's oppression. It was unfinished, and would need to be updated whenever the society it analysed changed.

But Hunt is not just an historical curiosity to us today. Recent years have exposed the social nature of disablement in a particularly brutal way. The decade of austerity, which deprived many disabled people of their most basic rights and dignity to save government money, has been followed by a pandemic and a deep recession. Man-made climate change has created more impairments – not least through viruses that thrive when wild animals' natural habitats are destroyed – and has made impairment harder to live with for many people around the world through rising temperatures, flooding, and extreme weather events. The energy crisis will leave many disabled people unable to manage their impairments by adequately heating their homes or running the equipment they need. Economic crises have devastating consequences in the health and social services, as well as disabled people's ability to pursue work and education. Accessible housing, education, information, transport, and work are still in short supply – even in rich countries like Britain – and there is no sign that the situation will improve while the other crises are going on.

Today, Hunt reminds us that we should never accept easy answers and easy fixes to these problems; they can only be

overcome by a thorough understanding of the world we live in, and a collective strategy to take control of our lives. Hunt's writings on the failed reform strategies in the '60s show us that we must be clear about what we are up against, and that not everyone who says they want to solve our problems is really on our side. His critique of a disabling society reminds us that the barriers we face to equality are all deeply linked; and we cannot truly defeat any one of them without getting to the roots of disablism. His modesty on his own achievements, his constant desire to develop the social analysis and the movement of disabled people, teaches us that we can never sit still; our struggle for freedom and equality as disabled people must adapt with each new social barrier and each change in how society is organised. For Hunt there was no great achievement, not even UPIAS, that could not be radically re-thought or dispensed with when our liberation struggle required it. What we do with these lessons is up to us.

Luke Beesley

Manchester, August 2022

Section 1: 'A slow rise of consciousness, a coming of age' – early writings and reviews

Hunt's earliest works, all published in **The Cheshire Smile**, were written during a stormy time for Le Court residents –when questions of their freedom to live, and be seen, as adults were raised within the Foundation and outside of it. On one hand, polite society had begun to feel deeply uncomfortable about the warehousing of people in residential institutions. More and more intellectuals and professionals were coming out and saying the obvious: that long-stay hospitals and the old 'workhouses' and 'lunatic asylums' of Britain were inherently oppressive places to live. At the same time, the strictest and most stifling aspects of the old institutions appeared to be creeping back into the Cheshire Foundation. Hunt and other residents found themselves in a very confusing situation: for the first time, public opinion was swinging to their side, but the reformers who led the 'Cheshire Movement' were slipping back into old ways.

The criticisms of institutions that Hunt deals with, particularly in his book reviews, are results of a revolution in social attitudes and values after the Second World War – although different arguments against segregated facilities came from different perspectives. Russel Barton and Micky Burns, both of whose work Hunt reviews, had seen first-hand how the Nazis had used institutional settings (concentration camps and prisoner of war camps) to strip inmates of their individuality: to control them, belittle them, and treat them as subhuman. On their return to Britain, both were shocked to find similar strategies of control used in psychiatric hospitals and boarding schools. In 1961, Canadian sociologist Erving Goffman gave scientific kudos to Barton and Burn's observations – offering a

comparison between the Nazi concentration camp and the American psychiatric hospital that focussed on their similarities. Other arguments, such as that by the economist John Vaizey, grew more organically from British soil. Post-war Britain was, for the first time in its history, able to offer work, education, and a meaningful say over how the country was run to most of its adult citizens. To be locked away in a long-stay hospital was to be denied those opportunities, and was intolerable to the modern sort of man. In all the types of objection to institutions, it was pointed out that they were doing the exact opposite of what they were supposedly for: they did not cure people or rehabilitate their 'patients', but often made them less emotionally and psychologically stable, less personally mature, and more dependent on others. By locking people away and controlling their social interactions, institutions prevented the personal growth and fulfilment that comes from the relationships and responsibilities that make up life in mainstream society.

This revolution in attitudes had some successes. In 1959 the British Government abolished Lunatic Asylums – where people with mental distress or learning difficulties could be locked away for the rest of their lives – and replaced them with a hospital system designed for shorter stays. As seen in Hunt's reviews, there were also a number of local 'experiments'; attempts to replace institutions for distressed young people and psychiatric facilities with self-governing communities. Organisations like the Cheshire Foundation and the Spastics Society, offering more liberal care regimes than the long-stay hospitals or asylums of old, benefitted directly from this turn in public opinion. Despite this, the most radical action on deinstitutionalisation was limited to people expected to recover from whatever condition they had been diagnosed with. For people with mental distress and those with a limited physical impairment, there was a real push from government and professionals to get them back into the community quickly; for older people and people with significant impairments or learning difficulties, no such pressure existed.

The Cheshire Foundation found itself in a difficult position on the institutional question. Its roots were in a Christian and humanist vision of care – and the individuality and dignity of the ‘patient’ were central to its vision. In practice, however, many of its staff, managers, and volunteers came from medical and army backgrounds where strict hierarchies, set routines, and respect for authority were essential to running any project. What residents’ lives looked like depended largely on who happened to manage or work in their Home: the conservative type who saw the Home as basically a type of hospital, or the progressive type attracted to the Foundation precisely because it offered an alternative to old-fashioned institutions. As Hunt wrote in his diary, ‘in one way the Matron of a C[heshire] Home has more power over her “patients” than the PM [Prime Minister] has over his subjects’⁶⁷

These tensions had played out in Le Court since Hunt moved in in the late ‘50s, but came to a head in 1962 in a series of deeply troubling events recorded in Hunt’s recently published journal. A new Matron had been appointed by the management committee to force some order onto the Home. Residents were told when they had go to bed, how much skin they could show when sunbathing, and that they had to address the staff by their last names. When Peter Wade, chair of the Patients’ (later Residents’) Welfare Committee objected, he was threatened with eviction. The eviction threat and new rules were dropped only after the Le Court residents and staff revolted – with nearly everyone publicly criticising the eviction to the Foundation’s Trustees, and several threatening to leave. The battle had been won, and the new Matron resigned: but many staff and volunteers who’d supported the residents were sacked in the following weeks, and pressure was put on them to break off friendships with residents (especially those between men and women). It was impossible for the residents not to realise how precarious their freedoms were.

Hunt’s response to these two contradictory trends was cautious. Hunt feared that he would be labelled a ‘troublemaker’ by management, and it was clear that this label

could ruin your life. By putting his own arguments about institutionalisation in reviews of other people's books or films, he could avoid directly attacking the Cheshire Foundation; while strongly pushing for a freer, more resident-led approach inside the institution. From Hunt's journal, it's clear that this plan wasn't entirely his own. Residents involved in the **Smile** were organising amongst themselves to walk a very thin line in the reviews section – praising ideas which the Foundation was rejecting, and criticising ideas it had adopted, without ever coming out clearly against its management, staff or trustees⁶⁸.

Hunt was fiercely loyal to the community that had grown at Le Court, and strongly believed that its relaxed approach to rules and hierarchies in the '50s had strengthened the residents' senses of self and emotional maturity. Whatever the Foundation's flaws, it had provided the space for this community to grow away from the long-stay institutions which stifled any hope of disabled people making meaningful choices about their lives. The Cheshire Foundation was a 'movement', capable of bringing principles of dignity and respect into relationships between disabled and non-disabled people. At this point, Hunt could not even think of undermining it, whatever fears he had about the course it was following. Nor could he support the radical demand, made Vaizey, to abolish residential institutions for disabled people entirely. The experience of Le Court had shown too much potential for a form of community life that did not belittle and infantilise its members.

This concern chimed with Hunt's religious beliefs. At this point in his life, he was convinced that to change the moral fibre of the Foundation for the better, one could not simply force management or staff to change their ways through embarrassing them in the magazine. Any real change must be made of their own free will; and only an agreement with management that came from a shared view that residents deserved the same choices and dignity as anyone else could be the basis of mutual respect in the Homes. This belief that a strong community between disabled and non-disabled people had to be a matter of free choice, along with Hunt's

commitment to the Foundation as a radical social force, gave moral grounds to his decision to 'avoid(...) the bad' and 'try to encourage the good'⁶⁹ rather than confront the institution head on.

These early pieces, unlike Hunt's later work, do come down on the side of charity, but more a vision of what charity could be than the actual efforts of the charities he saw around him. Hunt's 'real charity which does not 'do people good' from above'⁷⁰ might be better thought of as what we call mutual-aid today. Instead of one-way traffic, with the disabled person grateful but powerless in front of their helper, Hunt's vision involves a two-way relationship. The disabled person receives support to live a meaningful life which they choose for themselves, but in turn gives something to the helper – a deeper understanding of human dignity and freedom, and the chance to be part of a real, blossoming community which they build together. These ideas are fleshed out further in Hunt's writings in the mid-'60s, where the question of what disabled people offer society is discussed at greater length, but his project at the start of the decade is to reform the Cheshire Foundation towards this vision. The Foundation's failure to listen or to act will set the stage for how Hunt's thought and activism develop through the rest of his life.

The Le Court Patients' Welfare Fund⁷¹ (1958)

Responsibility in one form or another helps to mature the ordinary person. So it seems to be a false principle for those in authority to shelter disabled people and manage their affairs for them as though mind were affected as well as body. Well-meaning parents and guardians often encourage complete dependence on themselves in this way, which is surely a cause of the lack of maturity often found in us.

At Le Court, our Patients' Welfare Fund helps to counteract this tendency, and forms a seemingly indispensable part of a Home such as ours. As the written constitution of the Fund puts it, the underlying objective is:

“to give the patients as a whole a greater share in the management of funds and the organisation of activities especially relating to their welfare, and to encourage them to raise and expend funds on their own initiative wisely and constructively. It is earnestly hoped that this will give everyone a real sense of having a substantial stake in our own home, Le Court.”

There had accumulated in the Warden's⁷² care various sums of money earmarked for outings, radios, general amenities, etc., which were freely handed over to the Welfare Fund at its inception in 1953. A committee of three, Chairman, Treasurer, and Third Member, is elected annually at a meeting of the whole house to do the actual administration, with the Warden in an advisory capacity only. The house also meets every month to hear how things are going, to give its approval (or otherwise) to projected schemes, to voice grievances or offer suggestions. We have our own bank account, proper books are kept, and a nearby accountants' firm kindly audits them annually.

The committee appoints a Canteen Manager and Assistant (the Canteen has a turnover of £1,500 a year); an Occupational Therapy

Manager who, together with a visiting instructress, looks after all the arts and crafts activities in the Home; and various people to order, collect for, and distribute papers and magazines. In conjunction with these heads of departments the committee see to all the business arising – ordering, sales, paying bills, stocktaking, etc. Also someone has to see to the purchase and maintenance of all radios (there is one in each room) and the Television. Our 16 mm. film projector (a generous present) has to be looked after, and films booked and paid for – we have a show once a fortnight.

Other duties of the committee include helping to arrange all kinds of parties, outings, and entertainments. Although much has of necessity to be done and decided by the staff, this doesn't detract from the responsible part taken by the patients, as represented by their committee. There are many letters to write, mostly thank-yous for visiting entertainers and presents or donations.

You can imagine that all this saves the administrative staff a deal of work, but the positive benefit that is ours would seem to be the more important. In those who actually hold some position the effect is very apparent, for they feel of use and gain an added interest in the Home and everyone in it. The jobs they are required to do demand some measure of tact, fairmindedness, and other qualities if they are to be done well, and of course it is a very good thing to be serving others. Acting as leaders in a community, and dealing with people, money, and business affairs, makes for social assurance that can be hard to come by for those in wheelchairs.

Ideally, responsibility for the Fund should be diffused over the whole community. Unfortunately, individual interest seems to be on the wane, but there is still a great deal of interest and support that would not be there at all if everything were done for us.

It is often assumed that Occupational Therapy is sufficient to fulfil the creative capacities of disabled people. But one can get awfully tired of making baskets and trays, and there is little incentive to overcome the inertia that disability can produce. That is not to say that Arts and Crafts do not have a very real function, but it is surely doubly important that mental maturity and independence be produced if full development is denied us physically.

Perhaps one day we will be given more opportunity to contribute to society instead of depending on it. And perhaps, in a small way, our Welfare Fund, while performing such a useful function now, may also show the way to others, and make more people realise that a diseased body does not necessarily mean a diseased mind.

Institutional Blues

Two challenges to Authoritarian Organisation of Institutions⁷³

(1960)

Institution is a reasonable enough word – the family is an institution – but in these days when it's applied to a community it is almost always in a derogatory sense. People are terrified of being consigned to an Institution, a place of grey, blank walls, senseless regimentation and inhuman rules, of being put away, cut off from real ordinary life. Happily, in this country at least, places of that sort for the disabled are gradually becoming fewer. Those of us fortunate enough to be resident at a Cheshire Home will feel that we have come a long way since the days when our accommodation might have been the workhouse. However, it is important to realize that we are still living in an “institution”, although a very different one, and it is well that we should be aware of the dangers that are inherent in any community of this sort.

A beautiful view and a specially designed or “homely” building will mean little if the wrong ideas are still prevalent, if the people living in that building have no understanding of the demands, difficulties and pitfalls of community life. These two books deal, from quite different viewpoints, with aspects of life in hospitals. Much of what their authors say can be applied to the Cheshire Homes, and the study of both books is strongly recommended to those who have anything to do with small communities.

Dr. Barton⁷⁴ is Physician Superintendent at Severalls Hospital, Colchester, and has previously gained experience at many other mental hospitals. His book is a discussion of the symptoms, causes and treatment of institutional neurosis – what he calls “a mental bed-sore” – as found and observed in mental hospitals. Dr. Barton says that after four years in hospital many people are suffering from two diseases - the one that brought them there, and institutional neurosis. He insists that this latter is a separate disease, and not, as was once thought, merely an end-product of mental illness itself.

He shows that it is the environment that produces the disease (mental hospitals seem to produce it in an extreme form), and says that he “would like to have had the opportunity for more complete study of this man-made disease... observing the similarities and differences in other institutions”. Not that only institutions produce the disorder – an old person living much alone, or a handicapped child or adult over-protected by well-meaning but misguided parents, may develop many of the symptoms, although probably in a milder form than that described here.

The neurosis is “characterized by apathy, lack of initiative, loss of interest, submissiveness. and sometimes no expression of feelings of resentment at harsh or unfair orders...”, etc. Dr. Barton lists seven factors which are commonly found in the hospital environment causing institutional neurosis. These are: loss of contact with the outside world; enforced idleness; bossiness of medical and nursing staff; loss of personal friends, possessions, and personal events; drugs; ward atmosphere; and loss of prospects outside the institution.

Treatment for the disease is divided up into correctives for each of these factors :-

1. Great importance is attached to the person maintaining friendly contact both on the ward and with relatives and other people outside the hospital.
2. Activities are organized, beginning with simple personal care and social events, and leading to regular properly paid work in the hospital, and then to a position outside (it is vital to realize here that the organized part of it is strictly only for initial stages — the whole idea is to build up initiative and independence).
3. The changing of medical and nursing staff’s attitudes can best be accomplished by group discussion. “The attitude of staff needs to allow patient to be ‘somebody’, not, as often in the past, to prove that they are nobody. In order to bring this about the nurse needs to be treated as somebody”
4. Most important in the rehabilitation are personal events, especially spontaneous ones — “In the prevention and treatment of institutional neurosis the difference between what is personal and impersonal **first needs to be realized** and then accent constantly placed on the personal.”

5. Drugs can be greatly reduced in many cases with much positive gain and no harmful effects.
6. The provision of a homely, friendly, permissive ward atmosphere is extremely necessary for “The general impression a ward creates is important because it is continuously communicating to the patient whether she matters...”
7. It is attempted to give the person every assistance in finding accommodation. work and friends outside the hospital.
If there is pervading all these measures an understanding of the freedom and dignity of the human person. then the result is social rehabilitation in the fullest sense of the words.

Obviously some of these ideas apply only to conditions found in mental hospitals but with little modification, a good proportion of Dr. Barton’s insights and basic principles are just what we in the Cheshire Homes should be thinking about.

Mr. Vaizey’s⁷⁵ book is a vivid account of his experiences in several hospitals during the war, after he had contracted osteo-myelitis at the age of fourteen. For some of the time he was in pain of such intensity that he screamed and despaired daily, and always he hated and resented his sickness. But it was the attitudes of the people who looked after him that made the deepest impression on him. Some of them were kind, mature people who treated him as a human being. but there were others who helped to make his hell. At times when he most needed kindness and sympathetic understanding, he was often treated callously and jeered at for not bearing his pain manfully. At moments of terrible humiliation when he longed for some privacy, it does not seem to have occurred to anyone that he might have it — everything must go on amidst a ward full of people. When, owing to his position, saving stamps was about all he could do (it enabled him to keep sane), someone remarked, “I shouldn’t let my son collect stamps, it’s not manly enough.” And always there were the petty restrictions that served no purpose except that of giving those in charge an opportunity to exercise their authority.

Mr. Vaizey wrote his book mainly because he just had to get it out of his system, but the question he is asking implicitly throughout, and explicitly in the last chapter, is, what is wrong with a set-up which can allow some people to dominate others, often cruelly, will hear of no complaints and

tends to treat "the patient" as a second-class person? His answer to this and other questions of the same kind is that institutions are to blame – that they are bad things of themselves. He says that they impose patterns on people and detract from their humanity and individuality, and that they "give inadequate people what they want – power". And so he would do away with institutions as far as at all possible, and instead have day-hospitals, day-schools, day-prisons, etc.

Certainly Mr. Vaizey is a persuasive abolitionist, and there is something very attractive in the idea of day-centres providing work and care for handicapped people who otherwise live at home – in the future it may well be an ideal to aim at. But perhaps he is little too pessimistic about institutions – perhaps there is different solution to the problems they raise.

He provides a possible clue to one when he says "It seems to me that the essence of democratic society is that it should be easy for anyone – however young, old, stupid, ill-educated, or mad he may be – to complain with effect." Here Dr. Barton's ideas are relevant, for as another reviewer⁷⁶ says of his book "It challenges the whole conception of the authoritarian and hierarchical organization of large institutions for the appropriate care and treatment of individuals needing personal and social rehabilitation." Maybe then part of the answer is to have truly democratic institutions, where people can complain and be listened to, where there is no rigid authoritarian regime, benevolent or not, where there is opportunity for everyone in the community to participate in discussion and decisions.

One hopes that this is the conclusion that the Cheshire Homes are arriving at, for if they are not, then they will be out of step not only with men like Dr. Barton and Mr. Vaizey, but with the whole trend of modern social thinking, and they will run the risk of producing some people who love to exercise power for its own sake, and others who have had their aspirations to maturity stifled instead of encouraged.

Love and Growth

Some Thoughts Aroused by Reading a Much-discussed Book on an
Interesting Social Experiment⁷⁷

(1961)

Michael Burn⁷⁸ was somewhat sceptical when a friend, taking him to visit a place called Finchden Manor, near Tenterden in Kent, enthused about the community of boys and young men and their helpers living there — “no forced discipline and no corporal punishment, no limits of class or money – psychology is not talked, it is done – Christian behaviour is not preached, it is lived”.

But on that first visit he decided that he would need to spend several months at Finchden as a member of the staff before attempting to write about the work being done there. This book is the result of his stay, and it fully bears out his friend’s extravagant claims.

Finchden Manor houses about forty to fifty boys, mostly aged between fifteen and twenty years, a staff of nine, and Mr. Lyward⁷⁹ and his wife⁸⁰. The cause of their being at Finchden Manor is that the boys have been variously labelled as ‘maladjusted’, ‘depraved’, ‘beyond control’, ‘psychopathic’, ‘schizophrenic’, and so on. At the time that this book was written, it appeared that over two hundred former residents, once bearing similar labels, had been helped to live full and happy lives, and many of them had settled into highly responsible jobs or taken up successful careers. Perhaps most remarkable of all was the fact that several of the staff were themselves “old boys”, now helping others to find their real selves underneath the labels, just as they had once been helped. Undoubtedly, the secret of this achievement lies with Mr. Lyward, whose success with the “hopeless cases” has astonished other workers in this field.

To attempt a summary of Mr. Lyward’s thought in a few hundred words seems an impertinence doomed to failure. One gains from the book some idea of his breadth of vision, and there is no missing the author’s

sense of awe in the face of this living, creative thing which is Mr. Lyward's community. Mr. Burn is an artist who has conveyed with great sensitivity and understanding all he learnt at Finchden Manor, and he is always aware that he is dealing with something not to be analysed and put in a category. He knows that he cannot capture a mystery with his typewriter. Mr. Lyward himself asked him to "say it is unlimited, that's how our boys arrive at their limits". However, in the hopes that a clue may be given as to the importance of what is being done at Finchden, we shall try to sketch an outline of the ideas set out in this book.

Widening Awareness

The boys "are all cases of arrested feeling development": they are "emotionally disturbed" rather than "maladjusted". "Beyond all their wants, the boys need love". They needed "a freeing of the whole personality at the deepest level", and they needed to "learn to live". This learning to live means, not just a patching up or a getting rid of certain "objectionable traits", but "a gradual and infinitely thorough re-creation". As they abandoned their pretences and go back to a new beginning, the boys are gently "weaned", "loosened", "healed", given back their lives which in some way have been "usurped". It is generally the parents who have taken away the boy's own life, and forced him into a world of fantasy. Perhaps they do this by continued absence abroad and consequent "abandonment"; by failing to develop a spontaneous relationship with their son; by constant harping on moral standards that have no meaning for their child; or by their insistence that he should "get on" and be a success.

At Finchden Manor he is removed from the pressures that have had such disastrous effects. No-one makes him do anything or judges him in any way. Sooner or later almost every boy relaxes, and begins to know what he wants, rather than merely do what he thinks someone else wants him to do – or doesn't want him to do. Then, haltingly, the boys learn to accept the people around them, the "community of personal relationships". In this "widening awareness" of themselves and others, they often need the help of Mr. Lyward and his staff, depending on their strength and maturity, their unfailing sympathy, especially when, inevitably, their growth causes pain.

Inspiring and guiding, but never dominating, Mr. Lyward's faith, hope and love pervade the whole scene. "He had woven the work of teacher and healer so closely together that the two cannot really be separated. Education, in the sense in which he used the word, meant marriage of both roles." We would like to quote the whole book in attempting to give a picture of the man and his wonderful work.

Bearing on Cheshire Homes

One hopes that by now the reader is about to rush out to obtain a copy of **Mr. Lyward's Answer**, and he will be well rewarded if he does so. But perhaps he is wondering why we are devoting space to a subject that has little to do with the Cheshire Movement. Superficially, it is evident that Finchden Manor is a very different type of community from a Cheshire Home, but many passages from the book show that there are striking similarities beneath the surface. For instance,

"A truly loving family thinks of 'results' not only in terms of ordinary success or failure, but in terms of the spirit in which its sons have used success or confronted failure. Such a family, understanding the innate strength or weakness of its members, relates their achievement to the capacity of each and to the difficulties each has been forced to surmount".

It is as one would expect. While it can be only too easy to mistake a particular method for what is essential, there **are** certain basic truths about human beings and their relations with others that apply whether they are sick or well, young or old. On this deeper level we think there are many aspects of Mr. Lyward's inspiration that are universally valid, and might well be of use in the Homes. We will try to indicate just two of these here, and hope that the reader will make his own further application from the book itself.

Faith and Freedom

Firstly, for the Christian, and particularly one who has some position of authority in a small community, **Mr. Lyward's Answer** may provide a revelation. Religion is seldom mentioned, and there is no moralising at all, yet one cannot mistake the true Christian love underlying the

approach to every question. Mr. Lyward, knowing that the assent of a free will is the only assent that matters, would never force anything on anyone, least of all religion, and there is no account of the boys he helped coming to accept formal faith. There is a sense in which it is irrelevant. For the Christian, all growth is Christian, and faith is a gift from God. With his “love that is disinterested” and his “infinite compassion for others”, Mr. Lyward is leading his boys all the time towards a fuller, richer life.

The great danger in this sort of leadership is that a man might set himself up as God. But Mr. Lyward knows too well that the only true purpose of authority is education. “He stood in awe of power, which made misuse difficult, and never stamped the boys at Finchden Manor with his own image, nor bound them to him, nor insinuated his own theories. His life was spent trying to erase the disaster of such errors”. Again, from his innumerable letters to parents, explaining, pleading, reassuring, “True influence can only come as a result of relationship, and only where the relationship is not desired in order to exert influence”. And,

“I think it is now safe to say that he has at last complete confidence in me – not as a God (this was how as a child he trusted you), but as person. The echoing about which you write is, however, not too pleasant a reminder that you have remained God to him for too long, and that he still finds it very hard to accept anything less. As he becomes more accustomed to sharing the responsibility for his life with me — this is how to use his dependence to free him – he will not need to echo me”.

Then from another angle Mr. Burn says,

“The boys at Finchden Manor were all the while being helped, most of them **unconsciously**, to make a harder choice than others brought up under regulations which they had either to obey and be rewarded, or disobey and be punished... the boys in consequence were compelled to choose for themselves, without fear or inducement”.

But perhaps the following statement of Mr. Lyward’s is the nearest we shall get here to showing the depth at which he is working, “I wish to suggest that in thus pressing him back from ‘he thinks ought’ to ‘I want’,

am preparing him for a deeper appreciation of the truth in science, art and religion". There are hundreds more instances of such an integrated Christian vision in the book, and the reading of it can be an illuminating religious experience.

Possibilities of the Group

Mr. Lyward's profound concept of the group as a "healing agent" could be of great influence in the growth of the Cheshire Homes. "It would not be the first time that treatment devised to heal those who are sick brought help to those who had thought themselves whole". One would not wish to suggest that our residents or staff are "maladjusted" in the usual sense of the word, but it is surely true that there are immature and undeveloped areas in all of us. And it is obvious that a physical handicap will have certain repercussions in the realm of personality. Very little work has yet been done in the psychology of disablement, but it does not take a psychologist to point out the probability of the handicapped individual having attendant emotional and social difficulties to overcome.

It is perhaps not so obvious that the kind of person who works in the Cheshire Homes is likely to have his own brand of problem too. One can appreciate the fine work done by the staff, while at the same time realising that the Home provides a sheltered atmosphere for all residents, disabled or not⁸¹, and that people often try to work out feeling of insecurity or inadequacy by 'devotion to others'. We lack the space for full discussion of this very big question here, but one might perhaps generalise by saying that **the people who live in Cheshire Homes are, on the whole, kinder and more unselfish than those outside, but that they are also more likely to have personality problems whether by reason of physical disablement or previous environmental factors**. Even were this not so, it would still be well worth investigating ways of utilising the communities in which we live to resolve any problems that arise.

This is part of what Mr. Lyward does. He "made no claim for his community other than that it was one. He did not assert that it was better or worse or more or less Christian than other communities". But, "One reason that he now undertook far less interviewing than before was because the group had shown him how great a healing effect it could produce on its own". As "their living relationship with the community

developed” the boys came to know themselves more and more as persons. “The group worked... as a causal and all-important agent... and being themselves part of the community they became part agents, almost unconsciously, of their own growth”.

Quoted out of context as these phrases are, they are not remarkable; but taken with the rest of this book they can open up exciting possibilities for the future of the Cheshire Homes. Mr. Bruce⁸² says: “One hopes that what has been achieved at Finchden, although — like most pioneering — risking the intrusions of those who try to over-systematise, will also inspire other people, who may alter, add to, or subtract from it in certain particulars, according to the inspiration of each one”. It is to sources such as this that the Cheshire Homes must go if their inward development is to keep pace with their outward expansion.

“Throw Away Thy Rod” by David Wills⁸³ (1961)

This book is strikingly relevant to the Cheshire Homes and the question of their future development, although in fact it deals mainly with special school-homes for “maladjusted” children.

David Wills⁸⁴ has been concerned with maladjusted children and youths for over thirty years. In **Throw Away Thy Rod** he discusses the ideas and methods he has been evolving during this time, and his particular application of them in his present position as Warden of Bodenham School, near Hereford.

Under conditions that are necessarily artificial, Mr. Wills must try to create a substitute home (not an imitation one) for children who have been removed from their own natural homes. In his attempts to achieve this aim he has come to the conclusion that love is the one essential (an orthodox enough belief, but one that can bear repeated expression); and it is because of his awareness of what love is and his willingness to have it permeate all his thinking and doing that Mr. Wills has much to show us.

Arising from this basic principle of love there are, of course, certain instruments of love – concrete forms which it takes in the community. Chief among these at Bodenham is what Mr. Wills calls “shared responsibility”, a device whereby almost everyone living there shares the responsibility for running many aspects of the life of the home. Mr. Wills has had remarkable success with this method, and much of it seems tailor-made for experimentation within the Cheshire Homes. It is perhaps arguable how far “democratization” can or should go in the Homes; but, on the evidence of this book, real delegation and diffusion of responsibilities has a considerable influence for good in a small community, and we might take a lead from Mr. Wills in this matter.

Although very readable and full of compassionately told stories and incidents, **Throw Away Thy Rod** is not a well written book. The thought is not always clear, there are patches of worn phrasing, and the author’s

“whimsical” humour may not suit everyone. However, these are small defects in a work that can contribute so much to our understanding of love in its relation to society.

As Warden of Bodenham, David Wills has perhaps more opportunity than most people for applying his insights fruitfully. But whatever our situation we can learn from him that love, of God and our neighbour, not only implies doing “good works” but also using our talents to the full to influence the development and organization of our communities.

Living Proof – A Film About Le Court⁸⁵ (1962)

As a member of the community concerned in this film, I feel rather diffident about undertaking to review it. One of the dangers inherent in the project anyway (residents filming themselves), is that it might exhibit an unhealthy sort of mutual admiration. However, I think the film manages to avoid the worst excesses of this kind, and hope to be as successfully “objective” myself. Also I think the chance to discuss some of the wider implications of **Living Proof** is well worth the risk.

First, some credits and technical details. The film was made, over a period of about three years, by four disabled residents of Le Court. Members of the Film Unit are: Neville Thomas, founder and director; Barbara Beasley, secretary and script-writer; Laurie Mawer, cameraman; and Brian Line, sound recorder. They have had countless willing assistants and were given professional advice in the later stages by Ian Curtis⁸⁶ (producer of the BBC **Pathfinder** film on the Cheshire Homes⁸⁷). **Living Proof** is in colour, using a 16mm. film, with a linking commentary written and spoken by Barbara Beasley; it has a running time of 25 minutes. And it cost approximately £150 to make, most of which was generously raised by local friends who held several dances and a jumble sale.

The first showing of **Living Proof** took place in front of an invited audience in February of this year. A copy is now being loaned for publicity purposes, and in particular is to be used in the setting up of support groups in Hampshire. So far as one can judge audience reaction has been genuinely enthusiastic, and applications to loan a copy are coming in fast. (Anyone interested should contact the Unit secretary – naturally there are certain conditions as the copy is very precious).

At first sight one is struck by the absence of any serious technical faults in **Living Proof** – the makers had been apologizing for weeks before the premier so our expectations were not high! Many shots are “jumpy” in the old silent style, but this was due to the limitations of the rather ancient camera used. One soon forgot these and became absorbed as

the film progressed. The cutting (downfall of most amateurs) is excellent – Ian Curtis having provided the necessary ruthlessness – except in one over-long sequence where the shots of Farnborough Air Show are quite irrelevant to the main theme. The commentary binds the film together well and imparts a great deal of information, but is perhaps somewhat doctrinaire.

The most striking parts of **Living Proof** are the ones that show people doing out-of-the-ordinary things – or rather ordinary things by extraordinary means. Albert painting with the brush held in his mouth, and shaving himself without use of hands; Evelyn typing and sewing with her toes; Joy using her feet to comb her hair, light Andy's cigarette, and weave a scarf. By any standard these are fascinating things to watch, and they seem to have drawn the best out of the cameraman and director.

But although these are the scenes that one remembers particularly, I think they are not in themselves the most important things in the film. What comes over above all is the happiness and fulfilment that are possible in a Cheshire Home. The shots of people doing wonderful things by foot could have been taken in any hospital. But no hospital could have provided the framework of freedom and spontaneity from within which the people in this film give such an impression of actively enjoying life.

For me, **Living Proof** goes a long way towards justifying an insistence on a “liberal” kind of organization for our communities. I am convinced of the intimate connection between the obvious happiness and vitality of the people in the film, and the various “privileges” we have come to take for granted at Le Court. For instance, everyone being dressed and up for breakfast, every effort being made so that residents can go to bed when they want, the opportunity for constructive work, consultation of residents and their undertaking of many responsible functions, and so on – all these established freedoms have a very real relation to the fact of there being anything at all worth filming. **Living Proof** proves, to my satisfaction at least, that to give people (disabled or not) a high standard of physical comfort can be a basis for growth, but of itself it does not touch more than the fringe of their problems; only when opportunity for the exercise of freedom and responsibility is added, will growth and fulfilment of personality be likely to take place.

This connection between freedom and the growth of the person is one thing that occurs to me when thinking about **Living Proof**: another, which I should like to touch on briefly here, seems just as far reaching.

For the first time ever, probably, people with disabilities who are mainly on the receiving end of “charity”, have been able to show how things appear to them. They have presented to the world a picture of what being disabled looks like and feels like, from the inside, as it were.

I believe this idea of people expressing themselves and thus helping others to understand them, their aims and desires, is of the utmost importance in a field much wider than that of the Cheshire Homes. The charity that does things **for** people, while in no way to be despised, is but a shadow of true charity, which aims always to do things with people. And how can you do things with people unless you listen to them continually, unless you make an immense effort to understand what they think and feel about themselves and about the world? This necessity for an attitude of sensitive awareness so that any help offered may be relevant to the needs of the recipient, extends through every form of man’s assistance to his fellows. It is as important in relations between two people as it is in the international field – the lack of such sensitivity is one reason why generous aid to under-developed countries often produces resentment instead of gratitude.

It is hoped these remarks on a few of the implications in the appearance of **Living Proof** do not seem too fanciful. I believe them to be of consequence, and look forward to many more attempts at self-expression from residents in the Cheshire Homes. Certainly the members of Le Court’s Film Unit have every intention of continuing their contribution. Financed by hoped-for proceeds from this film, they will be starting on a new venture shortly. Under the Presidency of Miss Mai Zetterling⁸⁸, and with Ian Curtis’ continued advice, there’s no holding them.⁸⁹

Fighting Talk⁹⁰ (1962)

Two Lives by Peter Marshall⁹¹

Books by or about people with physical disabilities appear in increasing numbers. Fortunately, this growth in quantity is being accompanied by some kind of qualitative growth. The 'brave and wonderful' sort of book about disability is giving ground to some much more critical and realistic writing, indicating a slow rise of consciousness, a coming of age, amongst handicapped people. They are becoming gradually more aware of themselves and their situations, of their relations with 'normal' people, of their vocation in the world.

Something of this growth is shown by Peter Marshall⁹² in **Two Lives**. Mr. Marshall obviously has considerable literary talent, although the first half of his book tends to produce frequent mental indigestion as rich violent similes follow too fast one on another. He employs this talent with more restraint in the second part to describe and reflect on his situation as a person with a disability. An attack of polio when he was eighteen left him almost helpless; he is now dependent on others for most of his physical needs, and the rest of his life must be lived from a wheelchair. It is his sensitive response to these facts which concerns us here.

“Welfare Men”

Peter Marshall finds, as one might expect, that people tend to devalue him because of his incapacity. He is now in a very different world from the one he knew as 'normal' person. It is world of well-meaning but condescending Welfare Men, who offer a State Pension but not a job; a world where he is 'one of the worshippers at this Monday shrine of uselessness' (occupational therapy); where there are monthly film shows and outings to the seaside; a world too in which the cripple has to

conform to a pattern, where he is expected to be 'different', to be half alive, to be perpetually grateful for what is done or him.

Mr. Marshall refuses to accept this new half-life. He wants 'the worry, the pain, the frustration, the weather of the world'. He needs the ordinary world's acceptance – even its indifference. He wants to live, and write, and grow, and find himself as a person; he wants to be Peter Marshall, not a wheelchair. He says,

'People need re-educating about people like me. We're not a race apart, but that doesn't stop them making remarks like: "It helps to pass his time" or "It's ninety-nine per cent will-power" or "If I were him I'd stick my head in the gas-oven". And this sort of person relates everything to my wheelchair. If I'm angry or sad they say to one another: "Well, what can you expect, him being like he is?" But I got angry and sad before ever I got polio. It's about as sensible as saying: "That chap behaves like he does because he's left-handed." People need re-educating, but I wouldn't like the job.'

Process of Education

Yet however he tries Peter Marshall will never really get away from this process of education; whether he likes it or not he will spend the rest of his life teaching people about disability, showing them that a person's value depends on something other than his physical (or mental or spiritual) fitness. Mr. Marshall is rather over-emphatic in his total rejection of the 'world of the disabled', and also somewhat unkind to those who mean well but condescend. Perhaps one of the tasks of those who are dependent is to lead others gradually away from their 'charity from above' attitudes, towards the point where they give of themselves, and receive, on the same level as those they help. Mr. Marshall uses the word charity almost as an epithet of disgust; yet it is just real charity which does not 'do people good' from above.

But despite the reservations one might have about this and certain other aspects of **Two Lives**, Peter Marshall's views on his situation are of considerable importance, because to a large degree he expresses attitudes and feelings that are becoming more and more common amongst disabled people. They also want to do things, to take a real part in life, to live as normal and full lives as possible.

The emergence of this determination to 'fight' disability is brim-full of possibilities for the future; the handicapped person's efforts to participate more fully in ordinary life should not be seen just as a refusal to accept any limitations at all, although at times this is just what they may look like, and in some cases may be. For somewhere along this line of determined resistance to diminishment there lies a true resignation and acceptance of handicap. Such disabled people will have nothing to do with the false resignation of those who are content to sit back and give into their disabilities, to let others worry for them and look after them not only physically, but emotionally, mentally and spiritually as well. There will always be some who need such comprehensive care through no fault of their own; but for all those with some abilities left, one can say that the effort to use and develop their abilities is the pre-requisite for proper acceptance of their dis-abilities.

In **Two Lives** Peter Marshall highlights the handicapped person's need to fight his diminishment first before he can arrive at the required point for true acceptance; in this lies the special value of his book for all who have physical disabilities, and also for those who seek to help them.

So Briefly My Son by Mrs. Joan Neville⁹³

Mrs. Neville writes about her son Iain, who had muscular dystrophy and died at the age of fourteen. In ultra-simple style she tells how she and her husband fought to remain matter-of-fact about the disease which gradually destroyed all their hopes of a normal life for their boy.

You could not fail to be deeply moved by this book, yet there are no heroics in it, just determination not to despair or give in, and to make the most of each moment Iain had. Mr. and Mrs. Neville gave their son everything they could, but never in a clinging, over-protective manner. It was the constant concern of everyone in the family that Iain should be as independent of them as he could be right until the end when he was physically helpless.

Mrs. Neville's book, which can be read in an hour or so, gives tremendous insight into a tragic situation. It will help many people to understand what it is like to have a crippled child in the family, and also to see that it need not ultimately be a tragedy when it is faced in this sort of spirit.

Sickness in Christian Terms
In Time of Sickness by Hubert McEvoy⁹⁴
(1963)

I have strong resistance to ‘little volumes of prayers and meditations’; and have an even stronger resistance to books ‘especially for the sick’. Since **In Time of Sickness** is a collection of prayers and readings for people who are sick, it ought to qualify for my bias on both counts. So maybe it is some measure of this book’s quality that it overcomes my resistances to a large degree – even to the point where I can recommend it as excellent for anyone who wants to think and pray about their situation as a sick or disabled person. And because serious illness or incapacity comes to most people at some time or other, if only in old age, there are many who will find this an extremely helpful book to read.

Fr. McEvoy⁹⁵ is a Roman Catholic priest, and his collection is primarily for members of his Church. The first part of the book consists of prayers and readings for each day of the week. There are other sections and chapters on The Stations of the Cross, The Rite of Anointing, The Oil of Healing⁹⁶, and so on. Many of the prayers throughout are drawn from unusual and diverse sources, and some date back as far as the third century.

Everything in this book reflects Fr McEvoy’s sound approach to ‘the problem of suffering’, but naturally enough his attitude shows most clearly in the meditations he has written himself. Two quotations seem to give the essence of his belief in this matter. He says, ‘Sickness is but one of many human experiences. It should be approached, therefore, as intelligently as any other human experience’. Then a little further on, ‘This present way of life of mine has all the meaning and value for God that anyone else’s has, and that any other part of my own life had or will have’. The rest of his book shows that these are not just platitudes for Fr. McEvoy.

If have a reservation about **In Time of Sickness**, it is that perhaps it is more suited to those who are ill only temporarily, or have just been

“struck down’ and are fighting depression and an acute feeling of uselessness – rather than to the increasing number of those who regard themselves not so much as ‘sick’ but as handicapped or disabled. Somehow there is a distinction to be drawn here between sickness in the pneumonia, cancer, appendicitis sense, and sickness in the sense that applies to most of the people in Cheshire Homes – a permanent physical handicap resulting from polio or ‘chronic disease’ like rheumatoid arthritis.

Perhaps because the author’s own experience is of the sick-room type of illness, he seems to emphasize the passive side of acceptance, to stress the diminution sickness brings. This is somewhat out of sympathy with the more positive accent on rehabilitation, on living as normal a life as possible, that is so much part of disabled people’s lives today. Maybe the physically handicapped person of our time needs spirituality, or even theology, that takes explicit account of developments in the fields of medicine, social work, etc.

But none of this is meant to decry Fr. McEvoy’s fine book. **In Time of Sickness** will remain of value to those who try to see their sickness, whether temporary or permanent, in Christian terms.

Section 2: The “Role of the Residents” Debate

For Cheshire Foundation Trustees or Managers, the struggles in Le Court over rules in the Home were an attack on their authority. Senior staff had only been able to manage the Home by ignoring Management Committee instructions, and the Matron who'd tried to impose the Committee's idea of order had resigned under pressure from rebellious residents and staff. Until 1963, both Leonard Cheshire and the Foundation's Trustees were careful to limit the Le Court battles to the Home itself rather than let them spread to the whole Foundation. There were rumours that Cheshire would prefer a Management victory, complete with the eviction of troublemakers, and even a suggestion that his father (a prominent Trustee) had insisted on the new rules in the first place⁹⁷. Whether true or not, Cheshire and other Trustees presented themselves to residents as totally impartial. They could not interfere on one side or the other, whatever their personal feelings, and could only offer places in other Homes to anyone who got thrown out⁹⁸.

This position became impossible in the winter of 1963, when the Cheshire Foundation began to worry that it had badly overstretched itself. New Homes had been started wherever Cheshire felt there was a need for them, without any thought as to who would move in in future or who would pay for their bed and board. Both the type of resident and their funding now posed major problems. A study by Cheshire Trustees showed that most new residents would likely be older people with significant medical needs; supporting them in a Cheshire Home would, they believed, mean changing the age-range of residents drastically, and making the Homes' routines much less flexible. At the same time, many local councils, encouraged by the Ministry of Health's policy of nationalising care charities, disapproved of paying a charity to look after disabled locals when they could start their own hostels and cut out the middle-man. There were threats from some local authorities to rehouse

Foundation residents in council-run residential homes, which turned out to be empty but terrified Home managers at the time. The Foundation's fundraising also suffered; people asked why they should donate if their taxes already paid for housing and supporting disabled people?

The solution for Leonard Cheshire and the Trustees was a total overhaul of the way the Homes were run. The Foundation would seek much more formal and extensive contracts than previously from local Health Boards to house people who would otherwise go into hospital. This gave Health Service managers a significant say over how the Homes were run, which new residents came in, and how they would be supported. Nurses were too expensive and would be impossible to employ in enough numbers, so the Foundation would start training its own 'Nursing Corps' – semi-trained nurses to work for a fraction of the price – to meet new residents' medical needs⁹⁹. The Foundation's leaders could not have imagined that this solution would be acceptable to the Le Court rebels; instead of the liberal, partly self-governing community they had been used to, the Homes would now become medical environments with rigid routines. In place of negotiations between staff, residents, and managers over Homes' day-to-day running, they would be organised around training a new type of medical professional. A backlash was inevitable, but how could it be managed?

Cheshire seems to have settled on discrediting the resistance in advance by showing them to be a minority within the wider community of residents. In the winter 1963 edition the **Cheshire Smile**, he invited residents to write to the journal with their own views of what the role of residents in the Foundation should be. Cheshire was keen to 'encourage those who usually remain silent to speak up'¹⁰⁰; and to remind all residents of their moral obligation to think of others rather than simply their own freedoms:

No community can thrive unless it looks outward to something greater than itself. The original V.I.P.¹⁰¹ community failed primarily because it had no real end other than the well-being of its own members. (...) Our Lord's words "For he that shall save his life shall lose it; and he that shall lose his life for my sake shall find it" apply to our everyday life as well as to our eternal one. Everyone, I think, will acknowledge the truth of this.¹⁰²

It soon became clear that Cheshire had misread the mood. As was to be expected, many Le Court residents wrote in with a formal demand: residents should be allowed on every Committee of the Foundation – from those managing Homes to the Board of Trustees¹⁰³. They were, however, not alone: residents from all around England and Cornwall – who presumably knew little about the Le Court struggles – showed similar anger over how their Homes were run¹⁰⁴. Most damagingly, some members of staff, volunteers, and public supporters of the Foundation weighed in on the residents' side. For staff and patrons who'd worked in industry or public services, the idea of residents on Management Committees seemed as natural as trade unions or consumer groups joining a works council¹⁰⁵.

If Leonard Cheshire had been trying to show residents that he was fair minded, democratic, or interested in their views by starting the debate, his response to it showed the opposite. In the winter of 1964, Cheshire announced the debate was over. He argued that the residents were incapable of taking on any responsibility in the Foundation – they were either too immature and petty to act in their neighbours' interests, or had 'shoulders already bowed by disability' and were simply too physically and morally weak to handle formal responsibility¹⁰⁶. When Hunt wrote to the **Cheshire Smile** to attack this view of his community, Cheshire urged the editor to censor it (it's published in this collection for the first time)¹⁰⁷. Cheshire was, however, forced to make some concessions – Le Court residents were allowed to attend some parts of Management Committee meetings (although they could not vote and had to leave whenever decisions around staffing, finance, or admissions were made), and the Nursing Corps was first delayed, and then only rolled out in Irish Homes – a safe distance from critics in England and Cornwall.

These developments made it impossible for Hunt to trust the Foundation in the way that he had. Before, he'd seen Leonard Cheshire as a 'modern saint'¹⁰⁸ with deeply held beliefs in human dignity and community, which could be appealed to even when you disagreed with him. Hunt had been lukewarm to the idea of residents' representation at the Foundation's highest levels – after all, if you could convince the Foundation's leadership that communities heal themselves if left to their own devices, what would be the need? But now the higher-ups had decided there must be a strict, hierarchical, division between residents, staff, and managers in the communities themselves – making equality within them all but impossible. As far as Hunt was concerned, these

leaders were turning their backs on the Foundation's mission, leaving it directionless and at risk of becoming as authoritarian as the hospitals it had originally opposed. In his writings during the Debate, he not only adopted the demand for representation on committees, but in fact goes beyond it. His call for the Foundation to take inspiration from the New Horizon's project in the United States is not simply a demand for more representation or the rejection of Cheshire's new strategy. New Horizons was not a Cheshire-style Home with residents in its management, but a project run by the people who lived there – all major decisions were taken by residents, from its basic rules to how many people slept in each bedroom, to its staffing, admissions, and daily routine. Anything like New Horizons would require radical change in how the Foundation operated, and a considerable loss of power for its Trustees and managers. It's no accident that Hunt's appeal in his New Horizons article is addressed less to the Foundation's current leaders than to its progressive and younger supporters; who had been attracted to the Cheshire Homes because they were pioneering, and who may now see the need to pioneer again.

The Debate had two serious consequences for Hunt's work going forward. Firstly, it had proved that growing a community which empowered all its members, and in which everyone's freedom and equality were protected, simply was not on the agenda of the Foundation. The Cheshire Homes remained, for Hunt, the most sophisticated and humane type of housing for disabled people in Britain, but they had gone as far as they could in their current form and with their current leadership. Secondly, it showed that disabled people, acting together, were able to change the balance of power in the places where they lived. Together, residents and their supporters had forced Cheshire to offer some reforms to the Homes, and they had done this more or less unconsciously, with no evidence that residents had organised amongst themselves to pressure Foundation leaders anywhere except Le Court. The question after the Debate, for Hunt and people like him, was how to harness this power. What could disabled people achieve if they worked together to change segregated institutions? Was it better to try to organise disabled people inside of an organisation like the Cheshire Foundation, or outside of it? An exploration of these questions began in **The Next Ten Years**, where Hunt looks at the potential of the **Cheshire Smile** to bring together disabled residents in meaningful debate over the Foundation's future. He would return to these questions, with very different answers, over the course of the next decade as more and more

disabled people, both in institutions and the community, began to demand more control over their lives.

Governors and Governed¹⁰⁹ (1964)

I find it difficult to write you any short comment on ‘the role of the residents’ in the Cheshire Homes. The subject is so central, to my mind, that it immediately involves discussion of the whole purpose of the Foundation and of a great many related issues.

But, as a contribution to your debate I want to state my strongly held belief that the Cheshire Foundation (or at least that part of it for physically disabled people) should develop to the point where the disabled residents themselves come to share in the management of the Homes at all levels. I mean by this that there should be disabled residents elected as Trustees and on to Management Committees, and also that the members of each community-Home should share in many ways in policy making and everyday decision taking.

I believe that the present system, in which all formal responsibility is vested in people from outside the Homes, is fast becoming quite inappropriate to the real needs of the residents. If the Foundation does not integrate the residents into its authority structure, then I can see the day when the Homes will be as outdated, as an answer to severely disabled people’s problems, as are the chronic wards they seek to replace. Projects like **New Horizons**¹¹⁰ in America witness to this.

It seems to me that many of the troubles and difficulties in the Foundation at this time can be traced to the virtually complete separation between helpers and helped, ‘governors’ and ‘governed’, and to the lack of proper communications that ensues from this. In contrast to the early days of the movement, the whole authority structure now helps to emphasise and perpetuate divisions and classes within the Homes – especially the main separation between, on the one hand, Trustees, Committee members and staff, and, on the other hand, the ‘patients’. This amounts to a return to the hospital-type set-up which is so

unsatisfactory on a long-term basis for physically handicapped people, and which is foreign to the idea of a real 'home of your own'. This kind of managerial system tends to make those in authority both autocratic and excessively resistant to change, and also tends to produce idleness and irresponsibility in the residents.

I know have made only assertions so far, but my reasons for making them would fill several volumes of the **Cheshire Smile**, and anyway my notes still have to be worked into coherent form. Meanwhile, it would be a help to have reactions to my statements. Perhaps one of the Trustees would say why the development I advocate – which seems an obvious one to me and to many others – has not yet taken place, and at present shows little sign of doing so.

New Horizons in the U.S.A¹¹¹ (1964)

Many of the letters in the current 'Role of the Residents' debate suggest that the disabled residents should have more say in the running of the Cheshire Homes. They propose that residents should serve on Management Committees, and in various other ways should share in making the decisions which so vitally affect their lives.

An obvious query is whether anything of this kind has already been tried elsewhere. From all accounts it seems the answer is no – not yet anyway. So if the Cheshire Foundation does try an experiment along these lines soon, it will be pioneering again, exploring the possibilities of development that accords so well with the original concept of the Homes.

But although it is true nothing has yet been started in the way of management sharing in Homes for the disabled, it may not be long before someone else **does** begin. In a chronic hospital in Connecticut, U.S.A., some remarkable disabled people are working hard, together with their many friends, to found their own community-home. These people, who call their group New Horizons, are not only raising funds for their Home, but have produced a detailed blueprint of the kind of Home they feel they need. And they have some definite ideas on how this Home should be run in order to fulfil their aspirations for a completely adult life.

The draft plan for their Home is striking witness that ideas of shared responsibility arise almost automatically out of the situation of physically disabled adults forced to live some sort of institutional life. Obviously, the founder members of New Horizons are experiencing the difficulties that abound when an authoritarian-type regime is imposed on active minded adults on a permanent basis in a small community, and they are determined that everyone in their new Home will have the chance to contribute to decisions made.

In a brochure produced to explain their aims and objects, these people say:

‘The New Horizons residence would be the home of able handicapped persons, capable of making their own decisions and self-determining their own lives. Long-term “patients” in chronic disease hospitals and nursing homes simply do not enjoy such respect for their abilities and individual rights. The New Horizons residents would have varying degrees of disability, but their abilities would be of prime importance, Though the Home would provide adequate orderly and nursing help, as well as medical care, the emphasis would be on homelike, productive living. Each person living in the New Horizons Home would have the opportunity to participate in the management of such a Home no matter the degree of his disability. Again, it would be his abilities that counted. In chronic disease hospitals and nursing homes only able-bodied staff members are permitted to manage and run these institutions.

‘The administrator of the New Horizons Home would be chosen by the executive board of New Horizons, many of whom would be residents of the Home. In chronic disease hospitals the administrator is not chosen by the “patients” he or she governs, but by a Board of Directors completely separated from these same patients, and in many cases unknown to them. The administrator of existing hospitals writes the rules regulating the lives of those living therein. In the New Horizons Home, the residents would elect a Representative Council which would draw up recommendations to guide the smooth running of the Home, This Council would work with the administrator‘

Elsewhere further details are given of New Horizon’s policy on this question of authority and responsibility in the community. A Judiciary Committee is envisaged, to be drawn from the New Horizons membership, whose function would be to arbitrate in cases of disagreement within the Home.

‘If an important difference of opinion should arise between the Administrator and the Representative Council, the Administrator

should feel free to question any recommendation sent to her desk by the Representative Council. On the other hand, if the Representative Council feels strongly about a recommendation questioned by the Administrator, and discussion between them fails to bring agreement, the rule or problem under question should be referred to the Judiciary Committee for final decision'

What, if anything, do these proposals have to do with the Cheshire Homes? It is possible to dismiss them as the wishful thinking of a few sick people, and to say that their suggested system is both unworkable and unnecessary. But anyone with an open mind must surely ask himself if there might not be something in what they say, especially as many people in this country too are working for "democratic" institutions.

Obviously, the **New Horizon** plans are not applicable to the Cheshire Foundation just like that. We must find our new forms of government as we grow, must evolve systems and methods suited to the conditions here in Britain and in harmony with the basic principles of the Homes. But still a development along something of these lines seems not only feasible but highly desirable. For me, **New Horizons** testifies to the existence in man of certain fundamental needs which will not be denied, and to which repression is no answer at all. I believe that the desire which many of us share with the **New Horizons** members – to take a full part in the life of our communities – is both valid and important.

Perhaps it is significant that one of the sponsors of **New Horizons**, Group-Captain Leonard Cheshire¹¹², wrote to them: 'It is a cause that appeals to me greatly and I do congratulate you most particularly on having organised it by yourselves. I can well imagine the difficulties you have overcome and it is an enormous credit to you all that you have succeeded in doing so...'

The Next Ten Years¹¹³ (1964)

‘To read the back numbers of the Cheshire Smile is to trace the history of a social movement’¹¹⁴.

I think this phrase of Barbara Beasley¹¹⁵’s gives some indication of the job the magazine has done over the past ten years. Due largely to the work of Frank Spath we now have most valuable record of the growth of the Cheshire Foundation both in Britain and abroad. And of course the magazine has not only recorded progress and events, but has also had a great deal of influence on the Homes by linking them together and helping to create sense of common purpose throughout the Foundation.

We must hope that Frank Spath will still be editing the **Smile** in another ten years’ time – and it is these coming years that I want to take a look at for a moment. Now seems a good moment to take stock of the magazine and touch on the question of its future. What sort of journal should it be in 1974?

Firstly, I will assume certain things. (1) That the Cheshire Foundation will continue during the next ten years much as we know it today, perhaps doubling the number of Homes in this country and with many more throughout the world. And (2) that the **Cheshire Smile** (under a different name I hope) will remain the magazine of the Foundation, with especial reference to the Homes in Britain. I know these points are debatable, but they appear probabilities to me and provide some sort of background for the remarks that follow.

What about the present role of the magazine? One obvious function is the reporting of news in order to keep the widely scattered units in touch with the work of the Foundation as whole. Then there is the printing of information from ‘headquarters’ as a way of helping to maintain contact between the Trustees and the various Homes. Also, the magazine provides a link with the Cheshire Homes abroad and with the other autonomous Foundations that make up the Ryder-Cheshire Mission¹¹⁶.

And the **Smile** presents the Homes to the general public, telling of the work being done, of needs and problems, of how people can help.

All these functions are important ones, but there are two more which in my opinion are vital for the future healthy growth of the Foundation. The magazine can be a powerful medium for educating people (all of us) about disability, showing in a thousand ways that sickness and handicap do not affect the basic dignity and worth of anyone and that devaluing pity is the last thing needed. And the **Smile** can also act as a forum for debate within the Homes of all the questions that have to be raised and honestly discussed in any organisation like ours. It seems to me that these two functions are essentially bound up together. We can only 'educate' the public if at the same time we are educating ourselves by constant examination of our situation and a process of free exchange of ideas amongst everyone in the Foundation.

I believe these last two functions of the Cheshire Smile are going to be of increasing importance, and I should like to see much more emphasis placed on them in the coming ten years. Up until now there has been virtually no debate of the kind I mean in the Foundation; certainly the back numbers of the magazine show little sign of it (although the recent 'Role of the Residents' controversy was an encouraging straw in the wind).

As an organisation we are in danger of losing sight of our real purposes, of becoming too much absorbed by questions of finance, and bricks and mortar, and the prospect of more and more Homes. Our internal development is not keeping pace with the magnificent outward expansion. Understandably enough, when faced with an imperative need for more buildings, more beds, people are impatient of theory and want to get on and do things. But it is essential for us to realise that unless we are concerned with quality as well as quantity we shall fail to achieve anything really worthwhile. It is not enough to get people out of chronic wards and into comfortable and pleasant surroundings; as soon as they are there a host of new problems arise in a sense the problems that always arise when a reasonable standard of living is attained. It is of little use telling those in the Homes to be content with their lot and to try to help others less fortunate than themselves. However good this advice may be, simply to reiterate it as the answer to all difficulties is pointless. It is no kind of substitute for the reflection in depth that needs to be done all the time about the purposes of the Foundation and the ways in which

those purposes can be fulfilled in the actual conditions of life in the Homes.

Part of the concern with quality that I speak of will show itself in the encouragement of discussion at every level, even when this seems inconclusive and time-wasting, as part of a process of growth without which the provision of Homes for people is almost worthless. We need a developing body of thought about the basic issues of our existence as an organisation. And we can't create this without continual debate, criticism, thesis and antithesis. Gradually out of such an open dialogue will emerge a clarification of issues, a synthesis, a body of tested and valid ideas of our own. Of course, this elaboration of thought is only a part of the whole process of life in the Homes. And any written debate in the magazine is only a fraction of this again; but still it is vitally important in widely dispersed organisation like the Cheshire Foundation.

Even those who agree about the need for such debate in the Homes may still feel that the **Cheshire Smile** is not the place for it, on the grounds that public criticism and controversy will mean confusing our supporters by raising issues that do not concern them. I would agree that not every point is suitable for discussion in the magazine – although much depends on how the thing is done. But I believe the objection to public debate rests on a basic misunderstanding of the place of criticism in society, and an inability to see that it is precisely through such an honest and open clash of minds that truth is attained. Interested 'outside' readers of the magazine could contribute much to our discussions. We depend for continued existence on the support of the public, and in our search for the truth about ourselves as an organisation our friends and helpers should be included, kept informed and have their opinions welcomed. Also, the disabled people for whom the Homes exist need to be in constant relation to 'normal' society, need contact with the ordinary world if they are to find their true role in life.

Another objection to my plea may be that all this is too 'intellectual'. The average person in the Foundation has a practical turn of mind, and is working things out pretty well anyway. He wants a light-hearted journal – not a brains' trust that he wouldn't read anyway. Well certainly I am not asking for a magazine full of long abstruse articles on 'The Theory of the Cheshire Homes'. It is quite possible to combine the two approaches – intelligent debate and informal reporting and comment – and there is no reason why serious discussion need be stuffy. I hope the Cheshire Smile

will become at least monthly and will develop a large and lively correspondence section. Many people have points to make in a letter that they wouldn't know how to develop into an article. Their different views will be put forward, discussion can take place, and readers know that they are able to contribute to vital aspect of the development of the Homes.

So I would like to see the Cheshire Smile take the lead in fostering that growth of thought. In a depth that the Foundation needs; and then in another ten years it will have fulfilled the promise of its first ten.

Letter to the Editor of The Cheshire Smile¹¹⁷ (1965)

Sir,

I should like to comment on Group Captain Cheshire's "**Summing Up**"¹¹⁸ of the debate on the role of the residents in your December issue, taking advantage of his invitation for further discussion on the subject.

Firstly, I was delighted to note G.C.¹¹⁹'s strong backing for the idea of Residents' Committees having the right of access to Management Committees in all the Homes. I welcome also his reference to a "proper collective vehicle" so that the residents may not only "express their experience and recommendations, but contribute actively towards the running of the Foundation".

However, I am not quite so happy with other parts of the "**Summing Up**", and I want to query a few of the more important points.

G.C. says that the question, "Why aren't the patients appointed to the Management Committee and to the Trust?" is really only the question, "Why can't the patients run the Homes themselves?" in another form. If he means by this that the ideal situation would be one in which each of the residents had his own home, or at least helped his fellows run their own special community completely, then this is obviously true. There would be something very wrong with our attitude if we didn't value a normal, independent life, and aspire towards it.

But if the implication is that our request for representation on Management Committees is necessarily only a first step towards running the Cheshire Foundation for and by ourselves, then I must disagree. The whole reason for the existence of the Homes is that each resident, in his present circumstances, needs a degree of shelter. The helpers and staff provide this shelter, to put their contribution at its lowest valuation. New forms of community life, such as that mentioned by Dr. Agerholm¹²⁰ in her

Spring Conference speech¹²¹, may be evolved; scientific and technical advances may alter our situation and enable us to live more normally in society. But for the foreseeable future institutions like the Cheshire Homes will be needed, and so will the present form of help given by volunteers and regular staff. This evidently includes their assistance with management and administration.

Asking to share in running the Homes does not mean dispensing with staff and helpers altogether, and we would not want to do this even were it possible. We need able-bodied people's generosity in order to survive at all; we need interaction with them in order to lead full and happy lives. Wanting to be treated as adults despite our dependency does not involve a denial of these facts. We are really only pointing to a more important underlying fact – our unimpaired dignity and worth as human beings.

I have been discussing the idea of our participation in management for many years now, and I cannot recall anyone seriously suggesting that the Cheshire Foundation should be run solely by the residents. It is true that some people feel there should be a few homes set aside where only the most alert people are admitted, so that they could manage their affairs for themselves. But my own opinion is that this would simply be evading the issue. The real problem is to evolve a workable system of sharing responsibility in Homes where many of the residents, at certain stages anyway, are incapable of contributing much actively.

In his "**Summing Up**" G.C. goes on to refer to his experience in the early days of Le Court, when he gave certain residents a share in running the Home. He found that sometimes their conditions deteriorated rapidly, thus causing difficult and embarrassing situations. Perhaps it is necessary to draw a distinction here between administration and management.

The residents' involvement in day-to-day administration and work in the house, while desirable, can never really be legislated for, since it must always depend on the general health, mobility, strength and intelligence of those in a particular Home. But serving on a Management Committee is well within the capabilities of a good number of the residents in every Home, and presents hardly any of the same problems. And, however handicapped the other residents are, almost all of them are able to share to a greater extent than at present in the decisions so closely affecting

their lives, even if this is mainly through electing their more active fellows to speak on their behalf.

The last point from G.C.'s article I should like to take up is his reference to the residents who were given a say in admissions in the early Le Court. He says they only applied the criteria of like-mindedness and compatibility with themselves when asked for an opinion, thus jeopardising the first principles of the Foundation.

For one thing, it is not suggested that the residents be in the majority on admissions committees, so whatever their viewpoint it could not be enforced. Anyway, there is something to be said for not admitting people who would be unhappy, disturbing influences. And in fact most of the Homes do try to prevent this happening, as is shown by the trial period which is usual before admission.

But G.C.'s words on this question have another implication which I cannot accept. Whether he means to or not, he is suggesting that the disabled residents are incapable of going beyond their immediate self-interest, their own likes and dislikes; that they are almost bound to be uninterested in anyone else's plight. This appears to show a rather pessimistic view of human nature.

Paul Hunt.

Section 3: Writings on Institutions

The middle and end of the 1960s killed Hunt's hopes that self-governing and self-healing communities could grow from the residential institutions around him. In the Cheshire Foundation, the drive towards larger Homes and medicalisation progressed quickly; with new wards for 'heavy nursing' residents swiftly built onto Homes like Le Court. These pushed resident numbers up dramatically, limited how flexibly staff could support individual residents, and made resident-led decision-making virtually impossible. Things didn't seem more promising anywhere else – despite public concern about conditions in older people's homes and long-stay hospitals¹²².

The government and the National Health Service (NHS) had answered public uproar about the conditions in institutions by changing their locations and some of their admissions rules, rather than seriously looking at why the institutions segregated and dehumanised the people who lived there. Psychiatric Hospitals were shut, but often this just meant patients were moved onto specialist wards in local hospitals. Large hospitals for older people were closed, but those with support needs were funnelled into Local Authority Homes – which were still segregated and institutional, if nearer to where residents had lived beforehand. It was eventually accepted by the Health Service that young disabled people shouldn't be locked up with older people nearing their death, but their solution was to place them in Young Chronic Sick Units – which differed only in age range from the old system. Instead of seriously questioning how institutions worked, whether they could be turned into living communities, or how medical and social support might be arranged to avoid institutionalisation in the first place, the NHS

spent millions of pounds on new buildings where the old hierarchies of doctors, nurses, and patients would remain¹²³.

Nor was there any sign that either local or national governments were much interested in promoting non-institutional alternatives for disabled people. While more 'community services' – which provided disabled and older people with support to live in their own homes – were started around the country, these were meant to provide just enough help to stop someone going into an institution rather than for them take an active part in mainstream life. There were also strict rules around who these services could help, and many people with family living nearby would be turned down – regardless of whether their family could or wanted to support them. As a result, these new forms of help remained on the edges of the welfare system, and most of the government money spent on support for disabled people went into segregated residential institutions of one kind or another¹²⁴. While most disabled people lived with their family in a community like any other, the new services offered them little chance of taking part in it, and in many cases little help to remain at home if the family relationship broke down.

Hunt's vision of a self-governed residential community for disabled and non-disabled people appeared more and more distant in Britain, and this raised some fundamental questions for anyone who wanted to build a better, fairer, and more equal relationship between disabled people and the rest of society: Why did residential institutions tend to become stultifying, segregated, and cruel even when everyone involved claimed to want the exact opposite?; What could be done, in the here and now, to take away their worst features?; Were there other options on the table – either at home or abroad – which were preferable to disabled people's dependency on either the family or the institution?

Hunt was heavily influenced by the Canadian sociologist Erving Goffman in trying to explain why institutions slid back into their worst forms. Goffman argued that taking care of a

large number of people's physical needs in the same place – whether a prison, an army barracks, or a boarding school – inevitably led to 'regimentation and tyrannization'¹²⁵. To feed, house, and clothe everyone (not to mention put them to work or manage more complex bodily needs), an institution needs to insist on rules that suit the resources it has rather than the personal needs or desires of its inmates. A relatively small number of people (workers and professionals) give orders, and a much larger group take them. The people with power have little reason not to abuse it; ignoring the wishes of the inmates, or punishing them for not respecting the institution's often bizarre rules. The larger group have very little ability to resist and lose much of their personality and skills through living in a strictly controlled environment. Even in the freest of institutions, knowing that staff could introduce punishments or stricter rules at will makes inmates unlikely to challenge injustices, empowering those who run the place to do whatever they wish. Institutions are, then, likely to corrupt the people who work there, and enfeeble the people who live there.

Every residential institution needs a reason for being, an explanation for why people must live there rather than in wider society like everybody else. For hospitals and specialist homes for disabled people, Goffman argued, the institution and society had silently agreed to lie to one another about the needs of their inmates. Society found disabled and older people, and those with mental distress, troublesome and wanted them to be kept separate. They could not, however, blame the person for this – as they could easily with prisoners – or claim it was for their own or society's good – as was possible for army barracks or boarding schools. Doctors and other professionals offered a way out of this conundrum; by pretending that disabled people must be segregated to meet their medical or psychological needs, society could cheerfully send them away to be 'cared for'. In return, senior workers in the institutions were respected as 'experts' who understood the medical conditions of the inmates better than anyone else – especially the inmates themselves. The negative reactions of inmates to

their unbearable situations could be held up and described (often in scientific language) as evidence that they were really sick or emotionally unbalanced after all. The professionals' social status grew with respect for their expertise, while the inmate was trapped in an impossible choice – either to accept their inferiority, or to prove it in everyone's eyes by resisting the regime¹²⁶. There was every reason, then, for Hunt to be sceptical of appeals to medicine or psychology to explain why he and his neighbours lived in the way that they did.

Goffman suggested several ways of holding back the institution's worst excesses – although in his eyes it would be impossible to prevent residential institutions from being authoritarian altogether. Hunt adopted first Goffman's concern with how many inmates lived in a single institution, believing that a smaller number of residents would reduce the pressure to place authority in a few professional hands, and would give residents a fighting chance of influencing how the Home is run. Secondly, he concerned himself with what Goffman called 'private reserve(s) of the individual'¹²⁷ – spaces or relationships inside the institution itself, but which its hierarchies and rules struggle to operate in. The most important of these are single bedrooms (where a person cannot be watched or ordered around), and close friendships and romantic relationships (where inmates build bonds loyalty to each other, rather than the institution). Finally, Hunt's demand for co-management and representation on decision-making bodies is recast as a way of defending residents' current freedoms. While he becomes more sceptical that placing residents on Homes' or Foundation management bodies will lead to new kinds of community living, it may at least put pressure on those who give orders not to push their authority too far. At the same time, Hunt explored whether human and civil rights laws put any brakes on the more ridiculous rules he knew of in the Homes and Hospitals, and investigated what it would mean for the most rebellious residents to run a Home of their own within the Cheshire Foundation. Sadly, both proved a dead end. Hunt was informed in no uncertain terms by a legal scholar that private premises

like a Cheshire Home were exempt from civil rights laws, and break-away homes would still leave most residents stranded in institutions over which they had no power.

The picture we get of Hunt in many of the articles below is less of a visionary reformer with exciting ideas of how disabled and non-disabled people can live together, and more that of a soldier defending a city under siege. Residents' freedoms in institutions were constantly under attack; trying to keep hold of what had already been won and preventing things getting worse was often so urgent it was difficult to think much about advancing to a better position in the future. There are, however, moments when alternatives to the institution presented themselves to Hunt. Developments in architecture and rehabilitation (particularly of mobility and other aides) had made it possible to design individual flats and houses which many disabled people could use with much less support. Not only did this raise the question of why 'batch living' was necessary in the first place, but in the Netherlands and Sweden there were attempts to use this technology to encourage new forms of community life. In the Netherlands, Het Dorp ("The Village") was designed specifically for disabled people - with accessible housing, shops, and public spaces. Het Dorp proved that the key things non-disabled people used to live in society could be made accessible, but for Hunt the idea of a disabled-only village reeked of the desire to segregate that motivated institutional living in the first place. More attractive was the activity of the Fokus society in Sweden, which provided adapted flats in ordinary tower blocks in working class neighbourhoods. Disabled tenants were not only housed in the middle of existing communities, but their place in that community was treated as a social, not medical or psychological, problem. Their difficulties with education and work were seen as failings of segregated education, and support was given to finish their schooling and apply for jobs in mainstream workplaces. Any lack of family life or friendships was seen as a result of being shut away in special schools and hospitals, and Fokus supported tenants to meet their

neighbours and form bonds in whatever way made most sense to them. Having drinking buddies, lovers, or risky hobbies were considered choices any adult had a right to make, to be facilitated rather than policed. In short, Fokus tried to treat its tenants as grown-ups with the same rights and responsibilities as anyone else.

It was Fokus which had the most lasting impact on Hunt and, through him, on UPIAS. As the final piece in this section shows, it was also not unpopular with the more progressive sorts in local governments or organisations like the Cheshire Foundation. A series of complicated factors, however, prevented it from taking root in Britain. While these included resistance by many working in the institutions, who saw independent living as a threat to their livelihoods and control of their work, it also involved the organisation of employment, the way national and local governments decided to spend their money, the availability of decent transport, and how easy it was to reverse the effects of special schooling through mainstream colleges and schools. In short, Fokus offered an answer to the problem of what is to be done about institutions, but brought out very clearly questions about British society as a whole that Hunt and other disabled people so far had only dealt with occasionally: why were disabled people excluded in the first place?; why was it that work, transport, and education were provided separately for disabled people (if they were provided at all)?; why, despite every politician and service planner openly advocating integration, was segregation such a stubborn part of British society? By the early '70s when these writings end, Hunt was not yet in a position to answer these questions, but in both these writings on institutions and his other pre-UPIAS articles and letters they show up increasingly often in the course of his attempts to deal with other problems.

Patients or People?
A Look at the Problems and Needs of People
with Severe Disabilities¹²⁸
(1965)

‘The young chronic sick’ is a rather unpleasant official term for people with permanent, severe, and often progressive physical disabilities. In this category come those whose incapacity is the result of such diseases as rheumatoid arthritis, multiple sclerosis, muscular dystrophy, cerebral palsy and polio, or accident.

No-one knows just how many people like this live in Britain, but it seems likely that there are several thousand who, at present, need some kind of institutional care. Mostly they want help with daily living needs, with dressing, bathing, toilet, maybe feeding, and do not have the sort of home background where this assistance can be given. So they must seek admission to Homes like those run by the Spastics Society or the Cheshire Foundation where the necessary services are provided.

But a proportion of these young or middle-aged people still find their way into chronic wards, amongst those who are aged, often senile and dying. Many of these places are a scandal in themselves; desperately hopeless and tragic relics of the workhouse¹²⁹ era, they cry to heaven for reform. But terrible as they are for people at the end of their lives, the effect on someone who may have many years ahead of him can hardly be imagined.

At last the Ministry of Health have formed a survey team¹³⁰ to consider the problem. So a group of us who come into this “young chronic sick” category, but who happen to live in far more congenial surroundings, decided we ought to put in a word for the consumer. We produced a report setting out some ideas on institutional living that we have formed from our experience in chronic wards and Homes of various kinds. What follows is a revised version of our memorandum¹³¹.

In chronic hospitals people usually have to live in one large ward, bereft of all privacy. When lucky enough to be got up for the day they are put back to bed in the early afternoon, mostly just for administrative convenience. They have to have a doctor's permit to go out, and visiting hours are infrequent. A little time-passing Occupational Therapy may be the only outlet for the often considerable abilities left them.

This kind of thing could easily be changed. Already there are some special units set aside for younger people, and it would be relatively simple to make more available throughout the country. Obviously, anything that can be done along these lines is more than worth doing. But in our opinion the objections to hospital life for the permanently disabled go deeper than unnecessary restrictions and unsuitable surroundings.

Not a medical problem

Most severely disabled people do not need the skilled nursing care of a hospital – except, like anyone else, in acute illness. The hospital set-up on a permanent basis inevitably tends to stifle their initiative and capacity for growth. The whole atmosphere, even where special units exist, is coloured by assumptions inappropriate to people's long-term needs. Whatever the theory, in practice the medical view overrides the personal and social needs of the individual.

Yet by definition the permanently disabled person is no longer a medical problem. The hospital has done what it can for him, the important thing now is to provide the opportunity for the fullest degree of personal development, with medical care in its proper subordinate relation to the needs of the person as a whole. This emphasis cannot be achieved within the hospital set-up, geared as it is to something quite different – the curing of illness or minimising of its effects.

The hospital is essentially an authoritarian institution. This is more or less appropriate to the job it is doing, and most short-term patients do not mind such a regime when it is directed to their cure and return home. Also, they can complain with effect, at least when they are better, if authority is misused. But the severely disabled person remains very much in the continuing physical power of the staff. He soon learns not to complain, partly because of this constant 'threatening' factor, but also

because administrations are unlikely to listen – particularly when they are short of staff.

Of course, those who work in chronic hospitals are doing an unpleasant job, poorly paid and in depressing and often primitive conditions. Some of them do not abuse the tremendous power they have over their patients, but unfortunately others do. In many instances the “chronic sick” have their rights as citizens disregarded – because they cannot exercise their right to leave an institution, and are not in a position to force a hearing when things go wrong.

Substitute home needed

The only real answer for disabled people who require some kind of institutional care is to have small Homes where they can take a share in management. As adults they would normally find a home of their own. Where this is impossible, the need is for a substitute home, not just for ‘accommodation’, however pleasant and well administered it might be. The fundamental requirement for this substitute home is that the residents should be able to share in the responsibility for running it. All the desirable freedoms and conditions for a full life really flow from this share. Without it, they can always be taken away by administrative whim, and there is none of that security which is so necessary as a basis for individual and community growth.

The hospital system of down-the-line management by a committee and staff, with the patient on the receiving end only is not good enough for the permanently disabled. It needs replacing by a much more flexible concept of authority and responsibility, with residents of the Home being elected to serve on the management committee together with able-bodied members. The details could vary with local conditions, with the level of intelligence, ability and general health of those in each Home. The principle of co-management is the important thing.

People need to be involved in, and to have some control over, decisions closely affecting their lives. In institutions this is not possible in the informal way it is in one’s own home. The kind of set-up we advocate would help to do away with the tremendous pressure on those in conventional institutions to become ‘little’ people. So often the disabled in an institutional environment come to think of themselves, and be thought of, as inferior beings rather than as the fundamentally equal

members of society they are. This is partly the result of a system where all formal authority, power and responsibility automatically rests in the hands of what amounts to a privileged minority – the staff and management.

Staffing

It may be that it would be hard to get people to work in the kind of Home envisaged. Certainly, a unit run on the lines we suggest within the usual hospital is inconceivable, as it would set up intolerable strain for the staff concerned. This is one reason why the Ministry of Health should encourage voluntary bodies to experiment with special Homes outside the hospital system. Many of the staff in such places could be untrained by hospital standards. The Cheshire Foundation Homes have shown how well this works, and also the immense value of encouraging voluntary workers. The small number of State Registered Nurses needed to give skilled help might be seconded from the Health Service without loss of seniority or benefits, and this could count as an important experience in 'social' nursing for them.

Given official backing, and perhaps initially the services of management consultants, there is every reason to believe that staff would come to accept ideas of shared responsibility. At present the 'care of chronics' is considered a nursing dead end. But again the Cheshire Homes, for example, have gone some way towards showing that this need not be the case.

In a properly run Home the staff can find fulfilment themselves through sharing in the life of the community. They lack the obvious rewards that come from helping to cure people and return them ordinary life. But in a special Home there is no need of the hospital's protective barriers between staff and patients. So a vitally therapeutic relationship becomes possible, with the staff's routine care for the resident's bodily needs becoming only the basis of a role that has more to learn from social work than from nursing. Today the whole trend of social thinking is away from paternalistic charity. The idea is to do things not so much to or for people, but with them, and to aim always at their independence and maturity. The application of this principle to the field of the severely disabled is long overdue.

A part of life

The disabled residents having been given the freedom, responsibility and security they need, there is hope that their Home will not become just a retreat from the world. It should remain open to society, finding its place in interaction with the ordinary world. And not simply for the benefit of the residents. Disabled people serve as reminders that sickness and impairment are part of life. A society which puts them away out of sight and mind is trying to avoid the whole idea of the existence of pain, disease, death – which is unrealistic, to say the least.

The cost

Naturally what we propose costs a lot of money. To what extent does this country have an obligation to help its sick or aged citizens? Perhaps Hitler had the common-sense answer in exterminating the useless members of his society. Presumably our reluctance to do that here implies a belief in certain religious or humanist values. It seems a pity that we do not follow these through to the point of seeing that all handicapped people are given the means to a full life in proportion to the prevailing living standard.

For instance, given that we do want to support ‘helpless’ people in reasonable comfort, it is anomalous to expect those who are unable to work at all to manage at home on Sickness Benefit or National Assistance payments. These are designed to tide over limited periods of unemployment, not as permanent answers to total disability. No adequate allowance is made for loss of earnings by relatives who provide care, or for other special expenses that may be involved.

Yet in hospital a person may cost the State anything up to £40 a week, and £10 or more even in a special Home. It appears that these large sums are available only if one accepts dependence on a voluntary or State body which retains complete control of the money – and your life.

Reallocation of funds

Reallocation of these funds might, at one stroke, solve many of the present difficulties of the severely disabled. A realistic grant made to every person who cannot work would mean that some of the “young chronic sick” could live at home where this is not possible now. It would

also mean that those who still needed institutional help could choose their own home, and because they would be contributing their grant to the upkeep would have the chance of a real say in the running of it. This could take away much of the dread of going into an institution, because it is precisely the sense of powerlessness that is so frightening.

An imaginative example

Severely disabled people probably get a better deal in this country than anywhere else. But it is an illusion to think that the National Health Service takes care of all their problems. It provides a tremendous background against which to work, yet it needs adapting and supplementing in many ways. Perhaps the care of “the young chronic sick” is a field where Britain can again give the world an imaginative example.

Legal and Human Rights of the Physically Disabled in Institutions¹³² (1967)

The following queries stem from fifteen years personal experience of living in residential institutions for the physically handicapped and 'chronic sick', and also from accounts given by many friends and acquaintances in similar establishments. I have in fact been extremely fortunate in the general standard of kindness and consideration shown me, particularly over the last eleven years, and no doubt some at least of my correspondents would say the same. It is also true that we have only rarely come across cases of serious physical mistreatment or neglect. Inevitably, however, where people are almost totally dependent on others for the most basic daily needs, and are being cared for in an institutional setting with all the special difficulties this creates, there is a tendency for staff to use the considerable coercive power the situation gives them. This may often be done with the best of intentions, but in the process some of the basic rights of the citizen in our society may be disregarded.

People in residential institutions are seldom in a position to insist on their rights being respected. They may be too frail or too inarticulate to protest vigorously and effectively. They may be afraid of upsetting the people who have to see to their intimate and constant needs. They may simply be too depressed and apathetic to speak up after years in authoritarian institutions where it is assumed automatically that they must do as they are told. Boards of management usually discourage complaints, if only because they are always short of staff. Almost invariably the inmates have no effective alternative to their present surroundings, and thus cannot exercise their theoretical right to leave an institution. They are usually dependent on state or charitable funds for maintenance, and so suffer from significant remnants of Poor Law attitudes – even if they are not living in Poor Law-type buildings¹³³, which a lot of them still are. These factors, and many more, tend to create an

atmosphere in which ordinary standards of civil liberty are not felt to be applicable.

The provision of a leaflet setting out the legal and human rights of people in institutional care would help to protect them against the depersonalising tendencies inherent in their situation. It would also help the staff by defining their area of responsibility more clearly than at present, and giving them guidance as to the limits society sets on the exercise of their coercive powers. Such a leaflet could be made freely available to Boards of Management, to staff at all levels, to inmates and their relatives and friends, to visitors and to interested people in general. This would be an important step towards the creation of residential institutions more suited to our times and to a democratic society. Of course, it is not possible to legislate for kindness and imaginative treatment. It is possible, however, to reinforce the instincts of staff and management who try to respect the rights and wishes even of those most dependent on them, and also to place a more effective check on the power of those who have a less desirable situation.

The queries below relate primarily to the type of Home for the physically handicapped I know best – those that are voluntarily owned and run, but are subsidised by grants for individual residents from Local Authorities and sometimes Regional Hospital Boards. Many of the points apply equally well, however, to privately run and financed residential and nursing Homes, hospitals, and sheltered workshops for the physically disabled; and to Homes, hospitals and similar institutions which are wholly run and financed by Local Authorities and Regional Hospital Boards. A lot of the queries are also particularly relevant to the situation of the aged in various types of accommodation. There is some application to the position of people who are in Homes and hospitals for the mentally ill or subnormal, but obviously special factors have to be taken into account in such circumstances, especially where those concerned are detained under the provisions of the Mental Health Act¹³⁴. The points below refer to people who are physically but not mentally handicapped. Finally, these queries have a limited relevance to the situation of children and young people in many kinds of residential institutions, and to ‘normal’ adults in general hospitals, Homes for unmarried mothers, maternity Homes and so on.

- (1) Is there any suggestion in law that a person who is physically handicapped is thereby deprived of any of his basic rights as a

citizen (apart from the provision that someone may be removed to hospital if he is being neglected at home as a result of chronic illness)?

- (2) Apart from the provisions of the 1959 Mental Health Act, is there a legally recognised category of 'diminished responsibility' – for example when someone becomes mentally confused through illness or old age – which allows other people to act regardless of an individual's consent?
- (3) Is there any suggestion in law that people in residential institutions (other than those detained in prison or similar establishments, or as mentally disordered) are thereby deprived of any of their rights as citizens? A protest was made recently about old people having their teeth and glasses removed automatically on admission to hospital. This drew from the Minister of Health a statement saying that they should be allowed to retain these items, which should be removed only on medical advice¹³⁵. Is it really correct to talk of the old people being 'allowed' to keep their things? Is it not the case that they have a right to retain at least some of their personal possessions, and it is the staff who should be allowed to take them away only under certain carefully defined conditions?
- (4) Is it true that treatment given against someone's will normally constitutes an assault?
- (5) If so, does this apply to people who are receiving 'care and attention' in residential accommodation, and would it cover such things as being forced to have a bath, go to bed, stay indoors etc.
- (6) Are the staff of a Home legally entitled to 'punish' residents by leaving them in bed for the day, confining them to one room or to the premises etc?
- (7) To what extent can a Home forbid visitors at certain times, or arbitrarily ban specific individuals?

- (8) Has a Home a legal right to insist on knowing where residents are going when they go out?
- (9) Can a Home require residents to go only to the 'official' doctor or dentist? What is the position about this in hospitals – can one refuse a particular doctor or nurse?
- (10) To what extent might a voluntary Home be bound by its published aims and objects, as a registered charity raising money from the public and also in receipt of Local Authority and perhaps Regional Hospital Board grants?
- (11) To what extent does the residents' (theoretically) free choice of institution legally bind them to accept its rules, whether known in advance or not?
- (12) A registered nursing or residential Home has an obligation to give adequate 'care and attention' to residents. What are the legal implications of this for 'rule making' and the authority of the staff? The position as I see it at this moment is this. If a member of the staff dropped a resident and broke his leg, or failed to call the doctor when he had pneumonia, this might be failure to give adequate care and attention. The resident could in theory sue for negligence, and his sponsoring authority might rightly be concerned. However, if he chose to do something risky or foolish – like sitting out in the rain, or staying up all night, or leading an active life despite warnings about a weak heart – then the consequence would be his responsibility alone, and the staff could require him to sign a statement to the effect that he had rejected their advice. This right to make one's own decisions as an adult citizen should only be overridden in an emergency when staff may have to take quick action to save possible injury or death either to the resident himself or to other people. There are many informal pressures that can be brought to bear on any residents behaving particularly unreasonably, and if all else fails they can of course be asked to leave.

(13) When expulsion of a resident is contemplated, has an institution a possible legal obligation to see that the 'accused' has a fair hearing? By a fair hearing I mean notice of the charge, a hearing at which witnesses may be called and evidence given by both sides (and not outside the hearing), with the accused having the right to be represented. A New Society article suggested these conditions for a fair hearing at any tribunal, and also led me to suppose that the points it was making might apply to expulsion from a residential institution.

(14) Even if a 'fair hearing' is not obligatory, might a Home not be required to give a good and serious reason before expelling a resident? A 'sentence' of expulsion from a residential institution may in some ways be worse than a prison sentence to an ordinary person. For someone who has put down roots over a period, it means permanent banishment from substitute home, friends, and work at one stroke, and the stigma of troublemaker will follow him throughout the rest of his life.

Cheshire Foundation Home¹³⁶ (1967)

At a time when so much effort is being directed towards helping the disabled to live in their own homes rather than in institutions, it may seem strange that the Cheshire Foundation is pressing ahead with yet more residential accommodation. Responauts¹³⁷, in particular, who are campaigning so vigorously for realistic financial provision to enable them to live normally in society, will perhaps feel that "institutional" facilities specially designed for them are a waste of precious resources. The fact remains, however, that even given an adequate state allowance, a proportion of the severely handicapped will still not be able to live at home – for the foreseeable future at any rate. And this includes some responauts. In most instances the people concerned have no relatives or friends able to undertake giving them the help they need. Their only alternative at the moment is a hospital ward. Even the Cheshire Foundation, with some forty homes in this country, hasn't so far been able to offer responauts the special facilities they require. But soon, thanks to the initiative of Dr. Margaret Agerholm, who is well known to many responauts and is now a Cheshire Foundation Trustee, another alternative will be available.

At Le Court, near Liss in Hampshire, which was the first Home founded by Group-Captain Leonard Cheshire V.C. in 1948, a new wing is being added which will incorporate every modern aid needed by responauts, and which will be staffed with their requirements in mind. There will be a total of fifteen beds in the wing, nine of them in single rooms. Both men and women will be catered for. At the moment seven places will probably be reserved for responauts. At least one of these may be kept open permanently for short-stay residents, since there appears to be an urgent need for suitable holiday accommodation for people being cared for at home. The remaining beds in the wing are earmarked for other heavily disabled people who, like responauts, need more help than the

Cheshire Homes have usually been able to give in the past. It is hoped that the first residents will be admitted by the end of the year.

How will this new wing differ from the ordinary hospital unit for respiratory polios? In one important respect it won't differ. Everything will be done to ensure the very highest standards of care and equipment, including provision of a standby electricity supply, so that residents' basic anxieties will be eased as far as possible. Although, unfortunately, the wing will still be unable to cope with the small proportion of people who need the really specialised services only provided in hospital.

However, the big difference from a hospital, the one which justifies the whole exercise, is that residents will be living in a community which is specifically designed not only to meet their basic physical needs, but also to encourage their aspirations towards leading full, independent and useful lives. Even the best of hospitals remains a most inappropriate place in which to spend the rest of one's life, however much the rules and traditions are bent by sympathetic and understanding staff.

At Le Court, which already has thirty-nine residents, there is the great advantage of a specially designed building which makes for the maximum degree of physical independence and activity. There is also an amount of freedom and scope for initiative probably never found in hospital, and only very rarely in other Homes for the disabled. Residents go out when they wish, have visitors at any time. They get up all day, and every effort is made to enable them to go to bed when they choose. In addition to the regular paid staff, voluntary helpers are an integral part of the Home; many visit from the locality to help during the day, while a succession of teachers, students, police cadets, secretaries and so on, stay for periods varying from a weekend to several months.

Outings and entertainments are organised by the residents themselves, and include trips to the theatre, to concerts, films and the races. The residents have their own funds for amenities, run a shop and a workshop, arrange programmes of both feature and documentary films, buy and maintain radios and televisions, own and run a communal car, raise funds, go out public speaking, write a monthly newsletter . . . These activities are overseen by a committee which is elected by, and is responsible to, a monthly meeting of all the residents. This committee is also the chief means by which residents participate in management and administration. Two of its members are at present serving on the Management Committee, which has previously been drawn only from

people outside the Home, as part of a two-year experiment. This is almost certainly the first time such a scheme has been tried anywhere in the world.

Apart from these and many other responsibilities undertaken for the direct benefit of the community, residents at Le Court engage in a wide variety of other activities. They run a Film Unit which is currently working on its fourth production, commissioned by the National Fund for Research into Crippling Diseases¹³⁸; they manage and edit the **Cheshire Smile**, quarterly magazine of the whole Cheshire Foundation; they write books and articles, study, run printing and photographic businesses, sell hand-painted table mats and reproductions. One man earns his living with the Mouth and Foot Painting Artists' Association. Facilities for all the usual handicrafts are available in the workshop for those who wish to use them. Everyone who can work in any way is encouraged and helped to do so, though the form his contribution takes is very much left to the individual to decide.

So responants coming into the new wing at Le Court will by no means be expected to content themselves with a passive role. This would defeat the whole object of setting up the unit, and it would also constitute a considerable threat to the present community. In any residential Home there is always the danger that residents will sink into apathy. The individual's need to exercise initiative, and to retain responsibility for his own life, can be swamped both by the consequences of physical and economic dependence on others, and by the tendency for administrative arrangements to become inflexible and to deal in numbers rather than persons. By increasing its total of places from thirty-nine to fifty-four, Le Court obviously runs a greater risk of becoming "institutional." Residents in the new wing will have a large part to play in meeting the challenges posed by expansion, and their contribution to the life of the Home will be of decisive importance. Developments at Le Court, now the Cheshire Foundation's centre for experiment, are of great importance not only within the Foundation itself, but also in the whole field of residential care for those who are disabled and dependent. Le Court is setting out to prove that a relatively large community can be run in such a way that it encourages initiative and personal responsibility, safeguards people's need for privacy, and fosters the maximum possible degree of integration with ordinary society.

Whatever the disadvantages of community living, in the right setting there can be many advantages too. All sorts of services can be laid on for a group that couldn't be for one person, and this may mean living a fuller life in some ways than might be possible at home. But undoubtedly the most potentially valuable aspect of living in a community of the disabled is the strength and support that can come from working together, from mutual criticism and encouragement, from co-operating in the development of ideas and activities. This is indeed something to set against the loss entailed in renouncing or having to give up one's own home. Le Court hopes that many responauts, whether as permanent members of the community or on holiday, will experience this truth for themselves during the next few years.

Letter to Hampton Inskip: 12th June 1967¹³⁹

Dear Mr. Inskip,

Since my memorandum on the future of the Cheshire Homes looks like a being a long time in writing, I thought it worth setting down the enclosed notes on the idea of a self-governing community for the disabled. I should stress that the notes are my responsibility alone, and I suggest that until there is a real prospect of something being done about the idea it should be considered only a theoretical possibility that other Le Court residents would be interested. I know that some of them are, in fact, but it would be wrong to involve them without their consent. But it would also be wrong, I feel, to form any sort of “breakaway” group at this stage.

My own feelings are very mixed. Although I believe the experiment must be tried sometime, and would like to be part of it, in many ways the last thing I want to do is to leave Le Court. But despite the efforts you and some other people are making here, I can't help feeling that the odds are stacked against Le Court developing along really desirable lines. It's partly the increased size, partly the way the Service Corps is going, partly a realisation that despite the structural changes effected, most of the time we can still only watch helplessly when senior staff make the wrong decisions or act destructively. Maybe a radically different structure is needed where there are residents who don't accept traditional ideas of the staff's authority. On the other hand, I've always felt that the ordinary institution ought to be able to keep such people and will lose much if they ever do separate off into special Homes. Perhaps the answer to the question will be clearer if the new Warden turns out to be a good administrator

Notes on the Setting Up of a Self-Governing Community for the Physically Disabled¹⁴⁰

(1967)

Throughout the years at Le Court there have been discussions about the possibility of setting up a self-governing community for the disabled. At one time about twenty residents (and some staff) were definitely committed to such a venture when it seemed that the Group-Captain was prepared to sponsor it. There might still be fifteen or so residents willing to take the risks involved. It is felt that if anything of the kind ever does materialise, it would be only fair that each resident now at Le Court should have the opportunity to take part provided he or she was willing to make a firm commitment in advance.

It would probably be best not to try to fix the size of the community beforehand, though the intention would be to keep it as small as would be compatible with economic realities and the obligations to present Le Court Residents. The eventual size would be decided by the community itself. Future applicants for admission would need majority approval for acceptance.

The main purpose of a new type of Home would be for the physically disabled to prove that they can run their own affairs adequately on a community basis, and to help them lead fully adult and responsible lives. It is hoped that the success of such a venture would lead to a re-assessment of the way in which many residential institutions are run – even if such a degree of self-government is not feasible in most instances.

The principal difference from a conventional Home is that staff and residents in positions of authority would be appointed by, and be responsible to, the whole community, which would take major decisions by vote on the basis of an agreed constitution. It is envisaged that, with certain safeguards, residential staff would share in decisions as full members of the community.

The main difficulty in the way of this venture seems to be financial. If the Home is to be registered as a charity, a way would have to be found round the rule that the managers of charity cannot benefit from its funds. It might perhaps be possible to set up a body of Trustees with limited or merely nominal powers of intervention.

Getting maintenance grants from Local Authorities would be onerous. It might prove necessary to employ a trained nurse initially to gain their confidence. Alternatively, if sufficient funds were obtained from a Trust or other source it might be possible to make a start first, and then apply for maintenance grants once established and able to demonstrate the provision of adequate 'care and attention'. A further difficulty would be getting Local Authority grants for Le Court residents at present maintained by the Regional Hospital Board.

There would be a number of advantages if the Cheshire Foundation was prepared to sponsor the experiment. Local Authorities would probably be more willing to support it from the start. A suitable house and some financial help might be forthcoming. The Foundation's name would give confidence to potential supporters. If things went wrong residents would still be within the fold. The Foundation's registration as a charity would eliminate the waiting period usual before a new venture can be registered. And, of course, from the Foundation's point of view, whether it succeeded or not there would be much to gain from being associated with such an imaginative experiment.

There are disadvantages too. Directives from the Trustees would presumably have to be obeyed, and these might conflict with the community's wishes (e.g., the Trustees do not allow individual Homes to appeal direct to national Trusts and organisations). However, it might prove possible to work out some form of associate membership which left the new community with its autonomy intact.

Heavy Nursing Units¹⁴¹ (1969)

Doreen Swift's article on the 'heavy nursing' wing at Le Court raises some interesting points¹⁴². I strongly support her statement that the Cheshire Foundation should try to help those who are even more severely disabled than many in the Homes at present. On some other issues, however, I find myself disagreeing with her. I should particularly like to question her concluding statement that the best way of helping the severely disabled is by attaching special units to existing Cheshire Homes.

I do not doubt that if this is done there may be certain benefits to both old and new residents and staff. But in my view these are far outweighed by the disadvantages, many of which have become evident in the last two years at Le Court. I hope the Foundation will conduct some alternative experiments before any major policy decisions are taken on this matter. My own belief is that, first of all, the attempt should be made to integrate fully the very severely disabled into ordinary-sized Homes (by the provision of extra staff, equipment, and facilities such as single rooms in newly opened Homes). Secondly, if separate units are thought necessary, these should be sited in or near towns, and not stuck on to existing Homes that are already quite large enough.

As Miss Swift acknowledges, staffing the new unit at Le Court has been a continual problem. It seems fair to assume that this is at least partly due to the isolated situation. If new Homes for the severely disabled were situated in or near towns, it would almost certainly be easier to recruit staff. The idea of building houses for married staff near existing, isolated Homes may be a useful expedient, but the necessity for it should surely be avoided in future. For everyone's benefit, staff should in general be living out in society at large, not in ghetto-like groups of dwellings attached to Homes.

For the severely disabled residents, the siting of Homes in populated areas would have other benefits as well. Relatives and friends would find it easier to visit, and many residents would not have to tear up their roots and move miles away from home. Together with the greater availability of voluntary helpers, proximity of shops, pubs, churches, cinemas and so on, these are factors which in my opinion outweigh any vague advantages drawn from attachment to existing Homes.

It may be argued that the attachment solution is cheaper both to run and to staff. Some services are already provided and can be shared, and the land usually belongs to the Foundation. It is true that running costs may be marginally cheaper, but it is doubtful whether any significant further savings are made once one reaches 30 beds or so. It is also true that land in or near towns is more expensive. But, given the will, sites can be found - as the Foundation has proved on occasion. And I have long been of the opinion that central and local government should help with the capital costs of voluntary Homes. The needs of the most severely disabled would provide the ideal issue on which to hinge a campaign to achieve greater government help.

A second major argument against Miss Swift's solution concerns size. If there is one issue on which residents of quite different outlooks are united it is that Homes should be as small as possible, and never in any case larger than 30 beds. By the addition of 15 beds in the new unit, Le Court now has a total of 54 residents, plus a large staff, which brings the total of people involved to well over 100.

For new and old residents alike, this is very big community to call 'home'. One cannot avoid quite necessary elements of institutional living coming in, Senior staff are busier, management committee members are less likely to get to know residents and staff. New staff cannot be introduced to everyone. Changes are taking place the whole time that are outside one's immediate sphere, yet which may affect one's life intimately. Communications are more difficult and must be made more formal. For both residents and staff, it is impossible to spend time with more than a few people each day if one is to get any work done – so there are many people one rarely sees or speaks to. The increase in numbers is undoubtedly felt as a threat by many residents, and it can eventually lead to apathy and withdrawal. Problems are so big, and so many people are involved in everything, that residents tend to resign

themselves to events instead of trying to influence them. The temptation is to retreat into a private world of one's own affairs.

At a time when both government and expert opinion, and the expressed preference of residents, favour small, personal units, it would be a great pity if the Cheshire Foundation repeated the Le Court experiment. This to my mind has clearly shown two things. The first is that the most severely disabled people can live active, unregimented, and un-hospitalised lives, given the chance and the necessary unobtrusive background care. The second point is that these things become progressively more difficult to achieve the bigger, and therefore the more impersonal, the Home becomes.

Observations on Planning a Home for Spastics¹⁴³ (1970)

The establishment of small residential institutions for the physically handicapped is a development of the last twenty years. Some active-minded young people still have to lead a miserable existence in a geriatric hospital when their relatives become unable to help them with daily living activities, but an increasing proportion can now enter the homes and centres set by voluntary organisations and local authorities.

In the best of these new-style institutions there may be a fair measure of freedom, unrestricted visiting, organised outings and entertainments, and the opportunity for various kinds of work and social activities. Placed in this more suitable environment, and given sophisticated aids to mobility and independence, even very severely handicapped residents can lead relatively active and enjoyable lives. With modern medicine many of them may live for something approaching the normal life span.

In view of the advantages of special homes over hospital wards, the main question seems to be how the money can be found to build enough of them to satisfy the need. But unfortunately the matter is not quite so simple. For one thing, there are great variations in the quality of the provision made in the different homes and hostels. Only a small minority could be described as tolerably civilised places in which to spend the rest of one's life.

The drawbacks

More fundamentally, it is possible to be sceptical about the extent to which the drawbacks of institutional living on a long-term basis are avoidable even in the most progressive homes. The undesirable effects of institutions on various types of inmates, such as patients in mental hospitals or prisoners, have been well documented. People in institutions tend to lose touch with their friends and relatives, but form only

superficial relationships with other inmates or staff. They may become apathetic, depressed, and uninterested in anything beyond the immediately personal. Deprived of many opportunities for exercising responsibility, they tend to lose or fail to develop their powers of initiative and decision. Although there are qualifications to be made this unhappy picture, there seems little doubt that traditional institutional life over a long period is profoundly unsatisfactory for most people.

At first sight the residents in the best homes for the disabled seem to be very different from the depersonalised inmates of other institutions. But closer knowledge suggests that despite the excellent advances made in these homes, many of the residents either exhibit the characteristics of institutionalised inmates to some degree, or are dissatisfied with the prospect of institutional living on a permanent basis. This raises the question of whether 'batch' living for the physically handicapped is not more a result of society's need to set apart its stigmatised minorities than an effort to fulfil the residents' real requirements. It is arguable that alternative arrangements for living out in the community should be made for all but the most severely handicapped. The fact remains, however, that there are perhaps a hundred homes and centres already in existence, and more are planned. It is therefore important to try to understand the factors which can make institutional life so unsatisfactory, in order to combat them as far as possible when new homes are being built or old ones adapted.

Total institutions

The classic analysis of the basic structures of residential institutions has been made by the American sociologist Erving Goffman¹⁴⁴. He says that the central feature of 'total institutions' is the breakdown of the barriers that normally separate the three major areas of our lives. As a general rule we live, work, and play in different places, with different companions, under different authorities, and without an overall rational plan. In contrast the resident in an institution may find all aspects of his life carried on in the same place, with the same companions and under the same authority.

In total institutions a sequence of activities tends to be imposed from above by a system of formal rulings and a body of officials, and the various activities are part of a rational plan designed to fulfil the

purposes of the institution. There is a bureaucratic staff organisation which provides many services and daily necessities for large blocks of people, and which exercises supervisory control over them. Staff and inmate groupings tend to be carefully separated, and to view each other in terms of narrow hostile stereotypes; two different and largely incompatible social and cultural worlds develop, with a basic conflict of interests pervading relations between them.

Goffman's analysis shows clearly that many of the underlying structural features of the total institution are present even in the most progressive of modern homes. It is thus not surprising that they produce some of the same undesirable effects on their residents as do the old-style institutions. The practical value of acknowledging the relevance of Goffman's analysis to hostels and homes for the disabled is that it suggests certain ways in which their basic structures can be broken up and so made less totalitarian.

Planning decisions

The siting, size, and layout of the building will have a significant influence on the residents' lives. Severely disabled people are in any case extremely dependent on their physical environment. Once admitted to a home they are also unlikely to be offered an acceptable alternative, so are unable to vote with their feet on the suitability of the arrangements made. Therefore, planning decisions concerning homes are of even greater importance than those for normal housing. This applies with special force, if Erving Goffman is used as a guide, to five aspects in particular

1 Siting

The siting of institutions in urban areas is desirable for many reasons, not least because residents have more opportunity to become integrated into the community. There is also a greater likelihood that residents' families and friends will be near at hand, or will at any rate be able to visit more easily by public transport.

When homes are situated in the countryside, trips out for residents tend to become infrequent major operations, undertaken in groups and with staff in attendance. But in a town the ease of access to shops, pubs,

cinemas and other leisure facilities, plus the greater availability of potential friends and helpers living nearby, make it far more feasible for residents as individuals to spend time away from the home. In terms of Goffman's analysis, this helps to avoid the dangers inherent in residents passing their leisure hours under the same institutional roof and authority, and with the same companions.

The increased prospect of recruiting staff who can live in their own homes is a further advantage of urban siting. Staff-resident relations problems are exacerbated when staff themselves live in or near the isolated institutions, and a hot-house emotional atmosphere tends to develop. It is better for everyone concerned if most of the staff can return to their families after work and maintain normal social contacts.

2 Size

Homes should be as small as possible, never larger than thirty or so beds. The smaller the institution, the less relevant will be Goffman's factor of the needs of large blocks of people being met by a bureaucratic authority. With increased size a home necessarily becomes more impersonal, communications are more difficult, and each individual has less weight in relation to the demands of the system. More rules are needed and fewer exceptions can be made if administration is to run smoothly. Elaborate hierarchies and rigid divisions of duties become more marked among staff, and the conflict of interests between staff and resident groupings is more pronounced. The greater the numbers involved in everything, the stronger the temptation for residents to give into feelings of helplessness and to resign themselves to events instead of trying to influence them.

The usual justification offered for having large numbers is that this lowers the cost per resident. But there is no firm backing for any of the different hunches as to what the magic economic number is. In his survey of a related type of residential accommodation, that for elderly people¹⁴⁵, Professor Peter Townsend found that although

'local authority officials often suggested that the problem could be met only in homes with fifty, sixty or more beds...our evidence does not confirm these assumptions. We found no evidence that [smaller homes] were necessarily more costly or less efficient to run'¹⁴⁶

In fact, the proprietors of many privately run homes remark that 'a home with twelve to fifteen residents would be an economic size'¹⁴⁷.

3 Single rooms

Single bed sitting rooms should be provided throughout a residential home, and these should be fitted with locks of the type that can be opened easily in emergency. A proportion of the rooms should have connecting doors so that they can be used as necessary for married couples or others who prefer to share. Since by this arrangement residents have a choice of sharing or sleeping alone, there seems to be no case for having larger dormitories.

Private rooms provide residents with a 'home' of their own, a sanctuary from the pervasive authority of the institution as described by Goffman. They are therefore an essential part of any programme to break up the traditional living arrangements of the total institution.

It is sometimes objected that having single rooms leads to residents withdrawing from the community. It is difficult to see why people should not have the opportunity to withdraw if they choose to do so. There is in any case no support for the theory that that provision of single rooms leads to fewer social contacts among residents. Peter Townsend found in fact that when 'a large number of single rooms were provided for residents, many of the old people followed independent interests and activities... but... community life was often stronger'¹⁴⁸.

Professor Townsend also says

'A general finding of the survey was that the more liberal regimes were found in homes with a large number of single rooms. There was little doubt that the possession of single rooms not only gave more privacy, but also caused the staff to treat the individual resident with more respect and reduced the need for rules designed to prevent possible conflicts of interest among residents'¹⁴⁹

In addition it is worth noting that 72% of the residents interviewed preferred to have single rooms (including 6% or so who already had one, none of whom, significantly, wished to change). Townsend suggests that the figure might have been even higher if a choice had actually been available. Another finding in his survey was that only 30% of the most

severely incapacitated residents, who could perhaps have been expected to prefer sharing, did in fact want to do so.

Apart from points already covered, an overwhelming case can be made for providing single rooms on practical, medical, social, and psychological grounds. There is no space to detail the arguments here, but one of the most important relates to the gains involved in having a personal piece of territory to which boundaries can be drawn. There seems to be a deep need in most of us for an area which is in effect an extension of ourselves, which we can arrange and decorate as we choose, and to which we can control entry. In multiple-bedded rooms, each person's living space is continually being invaded by other residents and anyone they may invite, in addition to staff, and there is frequently distracting activity or conversation going on. This may result in an underlying sense of injury and disorientation, and in all the conflicts associated with overcrowded living conditions.

4 Sex and marriage

It is vital that both men and women should be admitted to homes, and that there should be no artificial segregation between them. The disadvantages of strictly segregated or single-sex communities hardly need stressing. It also seems to be true that the emotional and sexual relationships which can arise in mixed communities, particularly when accompanied by strong bonds of affection and commitment, are an anti-institutional factor which makes it more difficult for people to be controlled by authority. This problem has been the bane of more than one authoritarian or paternalistic administrator's life.

Goffman suggests that the private household provides a kind of structural guarantee that the total institution will not be without resistance. If this is so, then making it possible for married couples to live in homes constitutes a particularly valuable line of defence against the pressures of an institution. Husband and wife belong primarily to each other, not to the institution. There is also the factor that marriage can be an important means towards emotional maturity, and is therefore another counter to the immaturity often created or perpetuated by a sheltered institutional existence.

5 Workshop

If at all practicable, residents should be helped to take up employment outside the home. Where this is not possible, they should be able to go to separate but connected workshop premises. These ought to be administered independently from the rest of the home, and preferably either wholly or partly by the residents themselves. They then have a further means of escape from the authority of the institution, moving daily into an area where there are special opportunities for personal initiative and collective responsibility.

More civilised

Even if these five main anti-institutional factors are incorporated, homes and centres are still left with a formidably difficult task. But at least the provision of a positively non-institutional building should contribute towards a more civilised group and personal life for the residents, avoiding the worst pitfalls of institutional living. There is no available research into homes for the disabled to support this assertion. It is worth noting, however, that the points advocated here were all recommended by the Ministry of Health in its 1964 Circular to local authorities, **Residential Accommodation for the Physically Handicapped** (Circular 22/65, appendix 1). They are also supported by the evidence and conclusions of Professor Townsend's comprehensive survey of accommodation for elderly people¹⁵⁰.

Although nothing definite is known about residents' wishes it seems likely that the arrangements suggested would be welcomed by the vast majority. To a large extent they simply provide choices and amenities which most people in this country either enjoy already or aspire to possess. There is no reason to suppose that the severely disabled section of the population has a significantly different attitude towards such opportunities for personal fulfilment. Until it is proved otherwise, it is surely right to assume that the physically handicapped prefer living conditions as similar as possible to the scale, privacy and freedom of the ordinary household.

Costs

Some of the features suggested involve increased capital expenditure¹⁵¹, and may also mean somewhat higher running costs. Two points should be borne in mind. The first is that any extra capital expenditure will benefit successive generations of residents, and will thus be spread over many people. The second is that if the purpose of the home is to give as full a life as possible to a group of seriously disadvantaged men and women, then every effort should be made to find the additional funds. The investment will pay many long-term dividends.

Underlying issues

The matters discussed here may appear to be relevant only to a small number of homes for the disabled, or possibly also to some similar types of residential institution. But the underlying issues are of wider importance and involve a large area of social policy. The basic questions being posed are these:

- How do we wish to treat the severely handicapped and dependent minority in our society?
- Should the standard of provision made for them be different from what we want for ourselves?
- Or should the community's treatment of its weakest members be based on their common humanity and equal rights, and on the principle of integration into normal life rather than segregation from it?

Letter to the Editor of The Guardian: 6th February 1972¹⁵²

Sir,

David Cohen¹⁵³ has been seduced by the obvious charms of Het Dorp, the Dutch village for the handicapped. He should have treated some of the public relations claims made for the venture with a little more scepticism. He might have noted, for example, that to enter and remain at Het Dorp it is necessary to belong to an elite minority of the severely disabled – that is, you have to be young, not too severely handicapped, and have no mental impairment.

But there is a more fundamental point to be made. Perhaps we all secretly wish that the severely disabled would go away somewhere together and be happy, leaving us to get on with the important business of leading normal lives. Large ghettos such as Het Dorp, however imaginatively designed and run, are surely more a result of this feeling than of the actual needs of the handicapped themselves.

It is true that a number of heavily disabled people either cannot or do not wish to rely on relatives for constant help, yet they find that hospital is quite inappropriate as a permanent environment. In Britain at present the only alternative may be an equally unsuitable residential hostel or home, probably isolated in the country, and certainly beset by the intractable problems of institutional living.

What is needed, I believe, is not a big final solution like Het Dorp, but small groups of flatlets incorporated in housing schemes throughout the country. Perhaps half a dozen severely disabled people could thus live out in the community, each as a private householder in his own home, but sharing some facilities and with daily care provided¹⁵⁴.

Such a scheme would not in itself solve the difficulty of participation in society, but also make it a lot harder for society to ignore the awkward fact of disability.

Paul Hunt

Parasite People¹⁵⁵
A Life Apart by E.V. Miller and G.V. Glynne
(1972)

Between 1966 and 1969 Dr Eric Miller and Miss Geraldine Gwynne of the Tavistock Institute, financed by the then Ministry of Health, and at the suggestion of several Le Court residents, visited twenty residential institutions for the disabled. They investigated five of these in some detail – the Le Court and Dulwich Cheshire Homes, a Local Authority Hostel, and two 'young chronic sick' units. In addition, they did some 'action research' at Le Court. **A Life Apart** presents their findings and recommendations. It is attractively produced and well written, and almost every page contains discussion material for residents, staff, and other interested parties. Aids to independence, attitudes to disability, admissions and staffing policy, size of units, 'happy' Homes, work, sex and marriage, staff and residents on Management Committees – most of the burning issues of this kind are dealt with at some length. No-one who is concerned with residential care for the physically handicapped will be able to ignore **A Life Apart**. That said, however, I must add that I have very strong reservations indeed about the book as whole. It would be most unfortunate if, instead of stimulating controversy, it became a sort of bible for residential care. If God is the author of this particular work, then he has taken to moving in mysterious ways indeed.

Dr Miller and Miss Gwynne look at institutions for the disabled as analogous to biological 'open systems'. They write in terms of input (such as inmates, staff, food, information), processing (dressing, bathing, inmates' activities), and output (dead bodies, staff who leave)¹⁵⁶. It sounds quaint, but the notion does render some interesting insights about the processes at work and the functions of arrangements made within institutions. Their analysis eventually leads the authors to the conclusion that:

'the essential characteristic of people who have been taken into institutions is not simply that they are crippled and, therefore, to greater or lesser extent in need of physical care, but that they have been written off by society. They are in effect socially dead¹⁵⁷. (The) primary task of institutions for the disabled, is thus to cater for the period residents have between social and physical death'.

Presented by society with this unenviable task, institutions for the physically handicapped develop particular ideologies and social systems to help them to cope. The authors identify two main approaches. The first they call the 'warehousing' approach. This concentrates on the job of prolonging physical life in the inmates, and sees them essentially as passive hospital patients. The second approach is labelled 'horticultural'. This typically places great emphasis on personal growth in inmates, trying to help them develop unfulfilled capacities and to lead as full and active lives as possible. Dr Miller and Miss Gwynne manage to find time to say some apt things about the warehousing approach and its attendant evils, and they do somewhat reluctantly see the virtues of what they call horticulturalism¹⁵⁸. But in my view they have not placed half enough emphasis on two basic truths. The first is that the warehousing approach has nothing whatever to recommend it and causes untold misery amongst residents. The second is that the liberal, 'growth' approach, whatever criticisms may be made of some of its theories and assumptions, represents a genuine advance towards securing the rights and freedoms of civilised life for many severely handicapped people.

Dr Miller and Miss Gwynne lose sight of these fundamental points, and are led by their neat theoretical division into proposing as an ideal something like combination of the warehousing and horticultural approaches within one institution. This is indicative of a serious misunderstanding of the reality of life for people in residential care. It simply is not possible to separate off the 'psycho-physical dependency needs'¹⁵⁹ of residents in the way they attempt. The so-called horticultural approach caters for these needs far better than the author's caricature allows, and the immediate priority is to persuade more institutions to 'go for growth' in a big way. Dr Miller and Miss Gwynne say that 'an institution which sets out to be a better place to die in is likely to be better place to live in.' I would reverse this and argue that a better place

to live in will be a better place to die in. This is not simply playing with words. The change of emphasis is crucial. A large majority of people in institutions for the physically handicapped at the present time are not 'terminal cases' – or at least not much more so than all men are.

I do not quarrel with the authors' graphic description of the residents as being in a sense 'socially dead', nor their insistence that one of the major problems in institutions for the disabled is coping with everyone's feelings about rejection, deterioration and death. But I do object to much of the analysis, and many of the conclusions, surrounding such nuggets of wisdom. All too often Miller and Gwynne have been led astray by the strange logic of their theories. To illustrate the kind of mess they have got themselves into it is perhaps only necessary to mention two of their dafter conclusions. They suggest the creation of yet another separate profession, this one to specialise in the care of cripples both inside and outside institutions. And they maintain that the skills of ex-service officers and retired colonial officials make them more suitable as heads of institutions than either social workers or nurses.

But really these are quibbles compared with my main criticisms of **A Life Apart**. Firstly, this was not a good piece of work technically. Dr Miller and Miss Gwynne did not have the resources to do a proper statistical survey of a representative sample of institutions, and they chose not to pursue the obvious alternative research method of immersing themselves in the situation and trying to understand it from within. They visited some institutions, but stayed in none. They did however spend a lot of their available time interviewing people, and the information they obtained is reproduced in the form of tables and referred to. This lends a spurious air of 'scientific' research to the book, as do the liberally sprinkled references and the bibliography. The authors disarm the reader by disavowing the possibility of an objective approach to social research, but nevertheless continually give the impression that their work is more solidly based than is in fact the case.

The information in the tables is clearly wrong on several ascertainable points; the results appear to have been affected principally by the imprecision of the questions posed in interviews. In addition, the 'sample' of five institutions from which information was collected is acknowledged to be quite unrepresentative of institutions for the disabled in Britain. All of them were within easy travelling distance of London. Both the voluntary establishments were Cheshire Homes and both quite untypical

of the Foundation as whole. There was no Centre run by the Spastics Society, the other major voluntary provider of care. No information is published about even such basic factors as the numbers, disabilities, ages, and lengths of stay of persons in residential care in the country as a whole. It is true that none of these defects necessarily invalidate what the authors have to say. But they do mean that we should not be misled by the appearances of scholarly research into thinking that the exercise was anything more than an idiosyncratic look at certain institutions by two outsiders who have considerable experience in other fields.

My second criticism is that Miller and Gwynne never really look at alternatives to the kind of institutional care there is at the moment. They are not interested in the question of what numbers of people with comparable or more severe handicaps manage to live out in the community, how this is made possible, or what kind of lives they lead. They mention advances in medical research, the development of sophisticated aids to independence, the growth of community care facilities, and the movement towards a decent income for all the handicapped – only to assert their essential irrelevance to the ghastly reality of residents' lives, or rather deaths – in a residential Home. But there is every prospect that within ten or twenty years factors such as these will transform the situation of the physically handicapped who at present need residential care. Already there are various experiments in non-institutional living for the very severely disabled, both on an individual and a small group basis, being tried in this country and abroad. They are all based on the belief that the great majority of people would not choose an institutional setting if a viable alternative was available, and the knowledge that the nearer institutions get to the privacy, size, and freedom of the normal family home the better residents are pleased.

It is significant that Dr Miller and Miss Gwynne say they 'came across no inmate who was fully self-supporting; those who can afford it presumably find alternatives to institutional care'. If they had followed up the implications of this one finding, it would have given them a perspective from which to examine the whole question more adequately. Instead, they take it for granted that residential accommodation in virtually its present form is an unpleasant necessity for many of the severely physically handicapped until some (mythical) future state of universal kindness and generosity is reached. Masquerading under the guise of 'realism', this attitude is in fact profoundly conservative in the

worst sense of that word. In the foreseeable future satisfactory alternatives to conventional batch living for the disabled can and should be found for a great many people. Of course, this does not solve the difficult question of those in need today or tomorrow. Nor do I mean to prejudge the matter of whether or not there is to be some kind of long-term role for traditional residential accommodation. The point in the present context is that it is impossible to devise proper criteria for assessing the quality of life in existing institutions without paying serious attention to the standards achievable in the best alternative arrangements.

Finally, there is the crucial question of the authors' own attitudes, which of course shape the whole of the book. They suggest that they have managed to work through some of their ambivalent feelings about the disabled. But it is instructive to note the use they make of two major writers when discussing the social and psychological situation of the physically handicapped. Erving Goffman is quoted to illustrate the difficulties and dilemmas of having visible stigma in society. But it is fundamental to Goffman's view that:

‘stigma involves not so much a set of concrete individuals who can be separated into two piles, the stigmatised and the normal, as a pervasive two-role social process in which every individual participates in both roles, at least in some connections and some phases of life. The normal and the stigmatised are not persons but perspectives’¹⁶⁰

Miller and Gwynne ignore this vital theoretical distinction, and perpetuate the view of the disabled as stigmatised persons in all respects. They also use Beatrice Wright's work on the psychology of disablement¹⁶¹ to bolster their description of all the psychological handicaps which follow inevitably, they suggest, from having physical abnormality. They omit to mention the theme which runs through her writings: that physical disability is not linked in any direct way with psychological behaviour or adjustment.

The kind of language used in **A Life Apart** is significant, too. Medical and psychiatric terminology is much in evidence; in particular the word 'pathological'¹⁶² crops up frequently to describe the behaviour of the 'cripples' and 'inmates'. Everyone seems to be under great stress, to be erecting defence mechanisms¹⁶³, and to be bitterly depressed (even when they make jokes these are called 'macabre'). The residents'

situation is very significantly described as one of 'hopeless adversity'. But Miller and Gwynne appear anxious to prove that they are as hard-headed as any of their tough professional colleagues, and a stern moralistic tone creeps into the psychiatric judgements of attitudes and behaviour. Residents are frequently accused of evading harsh reality (as defined by the authors), of paranoia and collusion, of scapegoating, vilifying, and canonising. Criticisms of their environment by residents are dismissed simply as projections of the distress they feel at their frustrating but unalterable condition. It is true that these kinds of judgement are commonly made by psychiatrically-orientated professionals even about ordinary people, but the picture of residents which is built up here is an exceptionally negative one. It seems they can do nothing right.

Lurking behind the godlike judgements of the authors there appears to be an idea of some form of 'natural selection'¹⁶⁴ which divides the world into the biologically saved (normal) and the damned (abnormal). Unto the elect¹⁶⁵ shall be given the good life, but the unworthy are parasites who can expect only an inferior form of existence. The notion of the cripple as parasite occurs explicitly half a dozen times; my dictionary says parasite is an 'interested hanger on, toady, sycophant; animal or plant living in or on another and drawing nourishment from it.' So much of this book implies that the severely disabled drain the 'normal' world not only economically but emotionally and morally too, and they really have nothing to contribute in return that is worth bothering about. The authors see such a vast gulf between the joys of normal life and the deprived, distorted, hopeless existence of the incurable cripple, that they cannot regard the residents' lives as having any real significance or possibilities for fulfilment.

It is not surprising that Miller and Gwynne have been deeply influenced, as we all have, by the devaluing attitudes current in our society towards disablement and economic 'parasitism'. What worries me is that they appear to be content to accept this particularly Calvinistic, competitive view of life **as reality**. In most of **A Life Apart** they fail to make the essential distinction that it is one thing to recognise the existence of harsh attitudes as a fact with which we have to contend, and quite another thing to go on from this to accept those same attitudes as a justification for assuming that far-reaching change in the lives of the severely disabled is out of the question.

The extent to which negative attitudes towards something like disability are a product of unalterable biological and economic forces is a matter for debate. What seems to me undeniable is that one of the factors in any progress towards a better society is the willingness of people to take theoretical and practical 'leaps' which sceptical common sense regards as unrealistic and idealistic. This is not to say that hard thinking, painstaking research, and cautious experiment are not indispensable. The point is that they become sterile without imaginative vision and commitment.

This question becomes most acutely relevant when social scientists study oppressed minorities such as the severely disabled. The fundamental reason why groups like the disabled in institutions exist as 'a problem' at all is the prevailing value system and priorities of a particular culture. When investigators themselves accept without criticism the very assumptions which have created and defined 'the problem' in the first place, then naturally they are liable to come to conclusions which simply reinforce the status quo: Dr Miller and Miss Gwynne end their book by saying that the most we may hope for is that individuals 'can be given slightly more effective support' during the processes of ageing, deterioration and dying in institutions.

In order for their study to have produced a more helpful conclusion, the authors of **A Life Apart** would have had to abandon their conventional assumptions about the parasitical severely disabled. It would have been necessary for them to substitute an alternative philosophy which emphasised the rights and dignity of the residents as fully human adults. Despite their good intentions, which are evident in some useful patches of their book, Dr Miller and Miss Gwynne have not risen to this challenge. They have instead done a hatchet job for the competitive society.

As I See It...¹⁶⁶ (1972)

Louis Battye's¹⁶⁷ recent proposal for widening the basis of Cheshire Homes Management Committee membership¹⁶⁸ is welcome. But I confess to some doubts about his idea of inviting representation from organisations such as youth groups and trade unions. It seems to me that anyone who is going to be asked to make decisions about other people's lives should first have given some proof that he or she is genuinely interested, and not just seeking the prestige attached to committee membership. But I also believe that where there are managing bodies, their members should be acceptable to the people whose lives they govern. I suggest therefore that all permanent disabled residents should have the right to nominate and elect the outside Management Committee members of their Home.

For many years it has seemed obvious to me that we must aim at a situation in which disabled people are in a position to choose whether or not to live in a community. They should be able to decide the size of any group they do live in, and of course ought to have full control over the group's affairs. Ordinary adults in our society take these things for granted in family life, for instance. There seems no reason why things should be arranged differently just because people are physically handicapped. So I regard it as extraordinary that most Management Committees of residential Homes are appointed without any reference at all to the permanent inhabitants, and residents themselves are usually barred from any formal say in management and administration. It seems to me an essential step forward to have some elected representatives of residents as full voting members of the Management Committee. It also appears desirable that all residents and staff should be entitled to attend Management meetings to express their views on the matters in hand. And this kind of arrangement should lead to a situation where an increasing number of major decisions are made by the community as a whole.

It would be wrong to set any artificial limit on how far this process of community responsibility could go. My own view, as I have indicated, is that large residential institutions for the disabled need replacing by financial and social arrangements which would make this a purely academic question. The fact remains, however, that because of the present size of most Cheshire Homes, and the way they are financed, it is necessary, for the moment at least, to have a majority of 'outside' members on Management Committees. The normal arrangement has always been that new members are simply invited on by the existing Committee, which has itself originally been constituted before residents were admitted to the Home. The Trustees have formal power to refuse to sanction, or to terminate, the appointment of each Committee member. But, except where informal consultation takes place, residents themselves have no say at all in who their rulers are to be.

The merits or de-merits of existing Management Committee members are not in question here. Even if democratic elections were held tomorrow in each Home, and every single member of every Management Committee was re-elected by residents in secret ballot, it would not affect the principle of my suggestion. When people have to some extent to be ruled by others, is it not desirable that they should at least be able to choose who their governors will be, and to replace them at intervals if they prove unsatisfactory? And what member of any Management Committee would want to continue in office against the wishes of majority of residents?

I can think of a dozen supporting arguments in favour of trying 'representative democracy' in the Homes. The details could be worked out, safeguards written in, a variety of experiments tried – perhaps initially limiting 'elected' places to a minority for instance. What I can't think of is an argument against the proposal which doesn't in the end boil down to one of the old, old objections to democracy. And they can be answered in the old, old way by asking: Can you devise a better system?

How about some reactions from readers. Is there devil's advocate in the house?

Young Chronic Sick Don't Want Units¹⁶⁹ (1973)

Radical criticisms of current Regional Hospital Board plans for young chronic sick units, put forward by the severely disabled themselves, have been sent by Alf Morris MP¹⁷⁰ to Sir Keith Joseph¹⁷¹ for his personal consideration. It was following Alf Morris's Chronically Sick and Disabled Persons Act¹⁷², which drew attention to the plight of younger disabled people living in geriatric wards, that Sir Keith Joseph allocated £5 million for providing 1,800 places in alternative accommodation.

But at a recent seminar held at the Centre on Environment for the Handicapped¹⁷³, a group of the severely disabled confronted doctors, architects, and administrators from eight regional hospital boards. They objected to the whole concept of the proposed units as being segregated, institutional, and medically dominated, and they maintained that except in acute illness (like anyone else) their needs were essentially social and not medical.

They were forced to live in hospitals only for lack of alternative care, finance, and accommodation. This was demonstrated, they argued, by the fact that even people who were completely paralysed and dependent on a respirator for breathing could live purposeful lives at home when they had the right financial and social support.

It emerged from the seminar that there had been no previous consultation with the 'young chronic sick', and none of them were represented on the committees planning the new hospital units - although the Alf Morris Act specifically says that the disabled should be members of committees which concern their affairs¹⁷⁴.

None of the doctors at the seminar put forward convincing reasons why the severely disabled need permanent hospital care, and several were quite clear that the only reason for admission at present was the breakdown of social support. It was equally clear that, although the hospital board administrators pleaded they were only working to a political brief, there had in fact been no directive to provide hospital units

for the severely disabled as opposed to experimenting with other kinds of accommodation.

The seminar was told that the present RHB¹⁷⁵ plans were backward-looking and prison-like in conception, and would inevitably create all the well-known institutional characteristics in their inmates. What the severely disabled urgently needed instead was a new domiciliary care service to provide help in their own homes with such daily living activities as dressing, washing, lavatory and feeding. In Sweden each disabled person had the right to up to four hours a day of this sort of help at home. In addition, the Swedish Fokus Society now had schemes which provided 24-hour care for the most severely disabled, who lived in groups of 12-15 flats integrated into ordinary housing blocks.

At another seminar in the current series being held by the Centre on Environment for the Handicapped, Professor S O Brattgard of the Fokus Society¹⁷⁶ gave details of how their housing and care schemes operate, and announced that the Swedish government had just agreed to underwrite the whole of the Society's future plans to rescue more younger disabled people from institutions.

Professor Brattgard said that 85 per cent of the Society's tenants used wheelchairs, over 50 per cent needed dressing and undressing, 20 per cent required feeding, and 33 per cent needed help during the night. Some had to have as much as eight hours assistance a day. Yet there were no restrictions, and tenants enjoyed full rights as ordinary citizens. They were represented on all Fokus Society committees, and they shared communal facilities in their block of flats with the non-disabled tenants. Professor Brattgard said that within two years of moving in, a high proportion of previously institutionalised or isolated tenants were married or co-habiting; 39 per cent went out to work; and 27 per cent were at university or another educational establishment. 74 per cent were going out somewhere each day. Yet, Professor Brattgard said, the cost per tenant for full care was only half the cost of a hospital bed and two-thirds that of a place in a nursing home.

With facts like these before us, is it too much to ask that the real needs and wishes of the disabled here in Britain should be taken into account before retrograde, institutional schemes to house them are implemented? Sir Keith's reply to Alf Morris is awaited by one group of the severely disabled with something more than academic interest.

Fokus Housing Scheme, Sweden

Meeting: Tuesday 26th June, 1973:
at Baden-Powell House, London¹⁷⁷

The Fokus housing scheme in Sweden was the subject of a meeting held on June 26th under the auspices of the Central Council for the Disabled. Mr J E Price-Jones, Royal Planning Officer of the Royal Borough of Kensington and Chelsea and Chairman of the CCD Working Party on Housing for the Disabled, was in the Chair.

Opening the meeting, Mr Price-Jones welcomed Professor Sven-Olaf Brattgard, one of the founders of the Fokus movement, who was to describe the scheme, and Mr Paul Hunt, who began the proceedings with a description of then housing situation of younger severely physically impaired people in the United Kingdom.

Mr Hunt suggested that housing provision in the UK for the majority of disabled people was very poor, but for the most severely impaired it was even more unsatisfactory. The number of severely disabled people who required daily help with personal care was unknown but must amount to several thousands. Many were cared for at home by their families. This was satisfactory enough in some instances, but often it meant that a disabled person led a life of isolation and restriction, unable to work and deprived of social contact. The remainder of the severely disabled population was, however, usually even more disadvantaged, as they could only be cared for in institutions. The odds were that severely disabled people who could not be cared for at home would find themselves, if not in a geriatric ward, then in almost equally unsuitable residential homes.

Mr Hunt struck out at the conditions under which the disabled usually lived in such places: treated like children, they were given orders not advice; all too often they lived in overcrowded conditions in ill-designed, isolated premises, eating poor food and conforming to a regime designed principally to suit the needs of the institution's staff; they had no opportunity for obtaining proper work but often had to labour at handicrafts or factory outwork for a pittance, they were forced to live together as a segregated group, society having rejected them as useless.

Faced with this appalling situation, disabled people were beginning to voice their discontent more strongly. He considered that the Government's decision to build over 100 more large segregated residential institutions was a gross misuse of resources. Radical solutions were needed: the first priority should be a national care service to help the severely disabled live either with relatives or alone as they chose. The Fokus scheme – which, unlike current and projected schemes in the UK, had been developed with the active participation of those whom it served – suggested an additional way forward.

Mr Hunt closed with a demand that disabled people should from now on participate in the decisions which affected their lives. The imaginative Fokus scheme illustrated the difference that such participation could make when compared with the retrograde institutional projects being imposed on disabled people in this country.

Professor Brattgard then gave a brief outline of the objectives and activities of the Fokus Society. The Society had been founded in 1964 to provide housing, service and day and night care to severely physically disabled young people who would otherwise have to live in institutions or be confined to the parental home. These were people who were partly or wholly dependent upon technical aids and personal assistance for movement, personal hygiene, dressing and undressing, shopping, cooking and transportation. The essence of the Fokus scheme was the inclusion of flats for such people in ordinary rented accommodation, but with personal assistance available round the clock. The overall objective was to help the handicapped person in his whole situation, the better to enable him to lead his life without unnecessary restrictions.

The Fokus scheme was based on several important principles, Professor Brattgard explained. These were that the handicapped person must be free to choose where he wished to live and must be allowed to live in an ordinary residential environment and to use his dwelling under the same conditions as others. On the other hand, he must feel secure, and this security was to be based on access to every necessary personal service. In addition, the handicapped person must be supported as necessary to enable him to choose, obtain and retain work and he must be given opportunities to engage in meaningful leisure pursuits and to make social contacts.

It should be clear, therefore, Professor Brattgard suggested, that the Fokus Scheme was more than a housing operation: The flats constituted

part of a way of life, the underlying philosophy of which was that the disabled person should be put into a position in which he could make his own choices and bear the responsibility for those choices.

The Fokus Society had begun its operations by raising, through appeals and voluntary activity, the large sum of S.K.¹⁷⁸ 11,000,000 and its intention was to use this money and gradually to allow the community at large to take over financial responsibility for providing severely disabled people with housing and service. Fokus was a nationwide organisation with a central directorate and local executive committees, the former being responsible for finances, co-operation with the authorities, planning, building projects and general counselling, and the latter for the practical work of administering the scheme. A typical executive committee would include representatives of local government – including the local social, medical, and occupational welfare services – of organisations of the handicapped, of the central directorate of the Society and of the disabled tenants.

Fokus had based its initial plans on a survey carried out in 1968 which had found among the 8 million inhabitants of Sweden approximately 1,000 severely disabled persons between the ages of 16 and 40 who could benefit from flats of the Fokus type and an approximately equal number of borderline cases. With the finance at its disposal, the Society could meet about a third of the need, it had decided to up programmes in 14 localities distributed throughout the country. Many new problems were faced, and much research was done. A task force of experts, including architects, rehabilitation specialists, consulting engineers and handicapped people drew up a conceptual scheme on the basis of which the detailed design of the flats and their locations and surroundings was planned. A fundamental principle was that every tenant should have his own apartment and that a single room, even if equipped with kitchen facilities and so on, could not be accepted as a long-term solution to a handicapped person's housing problems. All the units were planned for severely disabled people from the outset and were included in blocks of flats for non-disabled tenants situated in popular districts near the centre of towns: all blocks were provided with communal areas for recreational and social activities.

Going on to describe the flats themselves, Professor Brattgard showed various slides. He explained that, generally speaking, floor layouts were the same but that all interior fittings were detachable, allowing the tenant

to shape his dwelling as he wished, and adjustable for height. Flats were designed to put the tenant at the centre of activity on all occasions. Certain technical amenities were built in; for instance, the electrical controls were assembled in small moveable boxes which could be placed near the bed, in the kitchen or on a wheelchair, allowing the tenant to open doors, call for help, talk on the telephone, turn lights on and off, and so on. All apartments were connected to on-duty personnel by intercom.

Fokus also provides flats for families, Professor Brattgard continued, and all its units adjoined communal facilities open to all tenants, handicapped and non-handicapped. These included recreation rooms with TV, communal dining-rooms, rooms for physical training and exercise, and craft activity rooms. Specially equipped bathing facilities were also usually available, as well as clothing-care provisions and garage space for wheelchairs. Service personnel were provided with staff rooms and an office.

Service for the tenants was provided by staff employed by Fokus as necessary to supplement the local home-help and district nursing assistance to bring it up to a 24-hour service, enabling the handicapped person to receive help whenever he needed it, for instance to go to the toilet, get undressed or have his sleeping position changed. The help provided by local authorities amounted to a maximum of four hours a day. An important aspect of the full-care service was the attitude of the staff. Fokus staff had to be open minded – for instance, on matters of sex – and must never treat the tenant as a patient. The handicapped person's right to independence and to the management of his private affairs must never be infringed.

Professor Brattgard went on to explain that the transport service was another major factor for the Fokus scheme: an efficient service was essential to allow disabled people to make the social contacts and take part in the activities made available to them by placing them in the centre of the community.

Finally, on the question of jobs, Professor Brattgard recalled that, at the beginning of the Fokus scheme, only 8% of tenants had been in work whereas, two years later, 80% were either working or receiving education.

There was no limit on the degree of disability acceptable to Fokus: the criterion was the desire of the disabled person himself to lead an independent life. The Society never refused a person because of an adverse recommendation from a doctor because it felt that the matter was essentially one for the disabled person himself to decide in direct discussion with the Society. In pursuance of the policy of fostering independence, however, the tenant was expected to pay his own rent, service, electricity, food, and furniture: assistance was available from the state should he be unable to pay.

Professor Brattgard concluded by pointing out that the Fokus programme had enabled a group of severely disabled people who were utterly dependent on round-the-clock availability of help to live an active and independent life under secure conditions in a location chosen by themselves and as a member of the community, not isolated from it.

Mr Price-Jones thanked Professor Brattgard, describing the Fokus scheme as an inspiration which he hoped would lead to better efforts in Britain. He called for questions and comment from the floor.

Mr Gordon¹⁷⁹ of the Hertfordshire Cheshire Home asked what layout was used for family flats. Professor Brattgard replied that open-plan and conventional layouts had been tested and that it had been concluded that a closed-room layout with a large area for communal activities best met the differing needs of families' individual members. In reply to a further question as to whether Fokus intended to try to house all the 2,000 disabled discovered by its survey, Professor Brattgard agreed that this was the objective if funds could be raised or as and when local government began to take over the responsibility at present carried by Fokus. A helpful factor was the independent cast of mind fostered in its tenants by Fokus: tenants sometimes moved out into their own accommodation after a time, vacating Fokus flats for less rehabilitated people. Mr Gordon added a question, in relation to services performed by staff, about assistance with sex and Professor Brattgard replied that such help as could be given was, though this was of course dependent on the attitude of the individual attendants. Over a third of the tenants were married or cohabited.

Another questioner enquired about difficulties in obtaining staff and what training was given to them. Professor Brattgard admitted that there were difficulties: about 50% had to be replaced six months after starting work because they proved unsuitable. Tolerance and open-mindedness

were essential but very little specialised training or guidance was needed: training in home nursing was all that was considered necessary.

Mr Mayell, Housing Manager, Islington, asked what ratio of disabled to able tenants was considered best and Professor Brattgard explained that to make the 24-hour service economically viable 12-25 disabled tenants in one block of flats was necessary. But concentration of disabled people should be avoided, and they should be dispersed throughout a large block among able families with children, pets, etc, so that they might feel that they were part of a normal environment.

Mr Collinson, Housing Director, Lambeth, regretted that in the United Kingdom funds could not be obtained through the local authority as was apparently the case in Sweden. Replying, Professor Brattgard urged the advantage for the taxpayer of such a scheme as Fokus: the cost of maintaining a disabled person in a Fokus flat was half that of keeping him in a residential home. In Sweden, the government provided a pension plus the costs of technical aids, the county council was responsible for providing a free health service and might pay for a nurse, but the main cost fell upon the local authority, which must provide a flat and pay the rent if the disabled person could not, just as it must do so for the sick, the old and the unemployed. Mr Collinson added that he would like to see the money which local authorities in Britain were to receive to build hostels devoted to starting a Fokus-type scheme: he hoped there would be pressure for such a change.

Dr Maureen Tudor of the Royal Hospital, Putney, asked whether Fokus units were sited with a view to obtaining jobs for tenants and Professor Brattgard answered that, once having filled in the gaps in a disabled person's education, it was relatively easy to find him a job since employers received financial inducements to employ disabled people, who must however be paid a full salary.

In reply to a question about the methods used to integrate Fokus schemes into the community, Professor Brattgard agreed that this took a little time and some effort. Methods included a small intake of tenants at any one time, possibly the giving of a party to introduce them to their neighbours and careful preparatory work in the community. If a little trouble was taken there was usually no difficulty in achieving a very happy relationship.

Mr R H B Archer asked whether mental handicap was a bar to acceptance by Fokus and Professor Brattgard replied that in Sweden the county councils had a special organisation for the care of the mentally handicapped. An IQ of 70 – below which considerable extra support is needed – was roughly the level below Fokus did not go.

A questioner asked whether emergencies did not sometimes arise with which non-specialised staff were unable to cope, but Professor Brattgard felt that Fokus could not wrap its tenants in cotton wool in order to protect them from hazards which might befall anyone. However, emergency buzzers were installed at floor level in the flats so that if a tenant fell he could summon help.

Replying to a further question, Professor Brattgard suggested that it took between six months and two years to resocialise an institutionalised person. The questioner added that, at the home of which she was Matron, independence was fostered but that the disabled people were sometimes difficult and demanding and – especially, it seemed, when staff was short – lacking in give and take. Mr Hunt felt this sort of comment illustrated his complaints about the staff attitudes prevalent in British institutions. Another speaker felt that the staff of residential homes were often maligned – they might have a long way to go but so had residents, who were often selfish and apt to have chips on their shoulder. A speaker from the Star and Garter Home¹⁸⁰ did not agree: disabled people tended rather to suffer from too much pity; they would much rather be treated as normal and not dictated to nor controlled.

Mr Gordon pointed out that disabled people were the same as everybody else – that is, they were all different – but that they did need the help of their fellow humans which perforce made them special. Mr Hunt stated that he only asked for facilities on the lines of those available in Sweden: he did not think that this was asking the earth. Mr Gordon agreed but urged an independent attitude, rejecting the idea that the world owed disabled people a living.

A speaker from a London Cheshire Home commented that he had spent ten years in the home, which was a good one. They had not been unhappy years but there was no comparison with the happiness of living independently in one's own flat. The problem for the severely disabled was the constant need of help which, without a large income, was unobtainable: the speaker felt that the Fokus scheme offered the best way forward yet proposed.

Other speakers support this idea, though it was recognised that the very different financial climate prevailing in Britain would make a Fokus-type operation much more difficult to fund than in Sweden. Professor Brattgard closed by urging that Fokus should not be seen as a rigid system; he hoped that it might be possible to adapt it to British needs by taking its good features and using them as the times and local circumstances dictated.

Mr Price-Jones wound up the proceedings by thanking Mr Hunt for his contribution and Professor Brattgard for the exciting account which he had given of a first class scheme which it was to be hoped would very soon be introduced into the United Kingdom.

Section 4: “Controversy at its best” – Columns from The Cheshire Smile 1966-1969

The writings on institutions in the previous section are some of the most cautious in Hunt’s work. Often directed at non-disabled people, Hunt used them to try and build on the progressive ideas that many in the disability scene voiced publicly. Where he did use harsh words to describe existing institutions and their managers – most notably in his **Notes on Planning a Home for Spastics** – Hunt took care to appeal to some scientific authority to back him up. More often, Hunt appealed to the better instincts of the non-disabled world – their belief in science, in progress, in dignity – as defences against stagnating, if not worsening, conditions in institutions.

The columns Hunt wrote for the Cheshire Smile between ’66 and ’69 are the reverse side of this coin. Directed solely at Cheshire Foundation residents, they show Hunt at his most experimental and willing to play with ideas. As he notes in the second column, the amount of literature about disability was growing rapidly in the mid-60s; with everyone from charities to doctors, activist groups to government planners trying to figure out what should be done with disabled people. Hunt’s columns are real-time commentaries on the hodge-podge of scholarly articles, charity campaigns, and government enquiries that clumsily tried to find out who disabled people were, what they needed, and what a society like Britain should do for them.

Ideas, insights, and analyses from across this ballooning literature are picked up, explored, and often simply dropped by Hunt as dead-ends. He goes backwards and forwards, enthusing about certain new ideas before sharply contradicting them. He focuses above all on what he calls controversy –

where disabled people and professionals come to loggerheads – as the places where new ideas are most likely to be developed. Particularly interesting to Hunt are cases where disabled people in institutions refuse to gratefully accept the rules of their home, or where researchers or government officials are forced to show that policies on services or facilities for disabled people make no sense. Like any collection of magazine columns, the results can appear messy and self-contradictory. From these writings, however, certain basic themes emerge which will spur Hunt’s intellectual and political development.

From the standpoint of Hunt’s later work in UPIAS, two things in particular stand out. The first of these is a new suspicion of even the most progressive of the professional reformers of institutions. In his writings on the Williams Committee report into staffing in residential institutions, Hunt notes that even the good liberals and left-wingers who push for institutional reform basically aren’t interested in empowering disabled people. At best, their worldview fails to see any way of organising support so that the hierarchies in institutions are no longer necessary. At worst, they’re driven by the same pitying attitudes to disabled people that Victorian liberals held towards Africans, Indians, and indigenous people; viewing them as eternal children who cannot take responsibility for themselves, and must be governed by the more enlightened and humane.

The other is Hunt’s enthusiasm for self-organisation, for disabled people directly controlling organisations which address disability issues. At that point, the model for this was the Disabled Drivers’ Association (DDA), which was concerned with the quality of accessible cars and tricycles. Hunt was impressed with the freedom the Association had to make itself relevant to disabled people and to campaign on the issues that mattered to its members. Part of what impressed Hunt was the DDA’s ability to change its demands over time. Its members had argued it was all well and good getting an adapted car or trike, but what if you couldn’t get into the building you’d driven to, or you couldn’t use a wheelchair to get across a road or public square? The DDA had responded by widening its campaigns to

deal with a broader set of mobility issues, including the design of public buildings and access to public transport. When some in the DDA argued that the organisation should set its sights still wider and organise on all issues affecting disabled people, Hunt was a keen supporter. A 'trade union' of disabled people offered an opportunity to break with the limitations he'd seen in the approaches of professional reformers, and offered disabled people the chance to develop their own skills and understanding of their place in society.

The DDA never did become that kind of group, and it wasn't until UPIAS was founded in 1972 that any organisation of disabled people set out to collectively take on all the social problems associated with disability (or, at least, to decide which of these problems were the most important). Disability organisations led by professionals, however, continued to grow in influence. While Hunt only really recognises this as a problem much later, there is an inkling in these columns that, at the very least, the best way to understand why disabled people are in the social position they are is to look closely at where their wishes and demands come into conflict with the worldviews of disability professionals.

Comment – Autumn 1966¹⁸¹

It's nearly three years now since Sheila Ridley¹⁸² wrote the last of her regular pages of comment in the **Cheshire Smile**. I've missed them a lot. It seems to me that if there's one thing the magazine lacks it is a variety of consistent points of view, of positive slants. A page a quarter from me will hardly supply this need, if need it be. But as I discuss various topics in the coming issues no doubt my particular angle or angles will show, and I very much hope this will stimulate some sort of response. Letters from readers would help guide what I write in future, as I have few fixed ideas about how the page should develop.

However, there's one point at least I am clear about. I shall be writing only about things connected in some way with the Cheshire Foundation or with disablement. To me, much the most valuable of the Cheshire Smile's functions is to promote discussion in depth about the Homes and about the implications of living with physical handicap.

I want to start this time by picking up an item from the last **Cheshire Smile**. Reprinted from the **Social Service Quarterly**¹⁸³, it referred to the handicapped who live in institutions. After applauding the efforts of statutory authorities and voluntary agencies to transform dormitory and shared accommodation into single rooms, and to ensure reasonable freedom of movement, the note went on to say

‘(but) there still seems long way to go before residents are given a real measure of self-determination, and are allowed to take regular part in discussions about amenities. No-one would want to suggest that residents could assume responsibility for major administrative decisions, but there must be many domestic matters involving their comfort and sense of belonging, in which the decisions of the done-by are as important as those of the doers’¹⁸⁴

I find this a very revealing passage. It shows a clear advance on most past thinking about people in institutions, with its extremely welcome stress on privacy, freedom, and self-determination. But, that acknowledged, I feel bound to take issue with the automatic assumption that: 'No-one would want to suggest that the residents could assume responsibility for major administrative decisions'. I for one certainly would want to suggest just that.

It seems to me quite unrealistic to try to draw line between 'domestic matters', in which the residents can have a say, and 'major administrative decisions', which are reserved for the able-bodied. It would be very convenient if groups of people and issues could be divided up like this. Maybe it is possible to some extent with children, or with people who are very disabled mentally; but it is not possible with adults whose handicaps are primarily physical, and whose great need is for an environment in which they can realise the full range of their potentialities. Placing artificial limits on the residents' personal and social development can only lead to frustration, and eventually to disillusionment with even the most well-meaning consultation.

It may be that the residents' disabilities will in practice restrict the extent to which they can share in management and administration (though if it were policy to share out responsibilities, and the necessary physical help were given, it might be surprising how far this could go). But if the attempt to give people a substitute home of their own means anything, it means that you cannot put up **Forbidden** notices on any issue at all; nor can you assume that the residents' aspirations, and their desire to participate in the life around them, will not lead them into areas hitherto reserved for the able-bodied. And certainly you cannot assume, as the note from **Social Service Quarterly** appears to, that the physically handicapped are, or should be, interested only in their own immediate comfort and well-being.

It is as though disabled people, and especially those who live in institutions, are considered a quite different sort of being from everyone else. We appear to be thought of as irremediably¹⁸⁵ diminished not just physically but also intellectually, emotionally – and even morally, since we are supposed to be incapable of assuming responsibility. I believe this kind of attitude stems ultimately from an inadequate understanding of, and commitment to, the vital truth that every person, no matter what his circumstances, has the right and need to be treated as fully human.

Comment – Winter 1966¹⁸⁶

Living in the same house as the Editor of the **Cheshire Smile** has its advantages. One of them, for me, is that I usually see exchange copies of almost all the journals and newsletters in the disablement field. With practice, I can skim through the miles of print about parties, outings and fundraising events, slowing down only for the more interesting items and bits of controversy (alas, few and far between).

There are perhaps 40 or 50 British magazines related in some way to permanent physical disability, and one can divide these roughly into several groups. Some, like the **National Cripples' Journal**¹⁸⁷ or **The Responaut**¹⁸⁸ are published primarily by and for the disabled themselves. A second group are issued mainly for the members, both disabled and otherwise, of a society for specific disease – the **M.S. News**¹⁸⁹ and the **Muscular Dystrophy Journal**¹⁹⁰, for instance. Then there are the 'professional' magazines, such as **Physiotherapy**¹⁹¹, **Occupational Therapy**¹⁹², and **Medical Social Work**¹⁹³, chiefly for their own members, and not only about physical disability, of course. And lastly, there are a number of journals that have to be lumped together in a miscellaneous category: **Rehabilitation**, which is the quarterly put out by the British Council for the Rehabilitation of the Disabled¹⁹⁴, the **News Review** of the Central Council for the Disabled¹⁹⁵, and the **Cheshire Smile**, for example. If you add the ordinary medical and nursing press to this list, it becomes a really formidable one.

My recent browsing has been rewarded by a whole series of articles in **Rehabilitation** (which I used to think dull and too technical). They were all papers given originally to an international seminar on rehabilitation held at Oxford in July last year. Professor Nugent's¹⁹⁶ fine contribution to the series, 'New Avenues of Life', was abridged for the last **Cheshire Smile**. I find this kind of thing both exciting and encouraging, because at last the 'experts' seem to be coming down off their pedestals and saying things that make sense to those of us they are trying to help.

The **Spastics News** has been printing some lively items too. In particular, there was a letter in the August number from the disabled residents at the Oakwood Centre for further education, near Colchester. In a polite but outspoken exchange of views with their Warden, they discussed a number of issues that had arisen at the Centre. A few extracts are probably the best way of indicating the interest and value of this debate.

'From the point of view of staff going off duty we naturally accept the fact that half-past-ten is a reasonable time to go to bed, that is, until an alternative solution is found which will allow a greater degree of flexibility. What we do object to is the arbitrary nature in which bedtime is set for each individual. Our objection concerns the reasoning behind this arbitrariness, a reasoning which says, in effect, that we must go to bed because it is good for us. Accepting the present difficulties in staff recruitment, our position taken to its logical end would be to let the individual who chose not to go to bed at the specified off-duty time suffer if need be on his own part.

We are rather amused at Mr. Watson's assumption that we want more authority and less responsibility. The actual truth is that we want more responsibility in order to exercise the authority over our personal affairs to which we, as responsible citizens, have an indisputable right. This includes the responsibility of consulting, and submitting to the convenience of, the staff in matters concerning transportation to hospital appointments, etc.

[We do not] decry the facilities available at Oakwood – judged by present standards, they are indeed admirable. But this only adds to our argument that such facilities are not, in general, adequate for the true integration of the spastic into society, necessitating as this does the ability of each resident to invite individuals from outside into their room on a basis of privacy. If it is the ultimate aim of the Spastics Society to help the spastic person to integrate as an individual into the outside world as far as possible, as it should be, then a policy of providing single rooms wherever possible should be initiated.'

Good rousing stuff. As the residents themselves say at the end of their letter, it is in some ways a pity to air issues of this kind in public. But, on the other hand, there is a great deal to be said for such open discussion, and all concerned – perhaps, especially the Editor of the **Spastics News** – are to be congratulated.

Lastly, I want to present an accolade. Quite outstanding amongst all the magazines concerned with disablement is the quarterly, **The Magic Carpet**, published by the Disabled Drivers Association. It's full of useful information about mobility for the disabled, and it has forceful editorial policy on issues like the elimination of architectural barriers, provision of cars and two-seater trikes, the integration of the handicapped into society, and so on. Yet the magazine as a whole also seems to reflect the full range of opinion in the Association, and particularly impressive is the spirited and intelligent debate about matters of basic policy. I think it is no coincidence that the Association itself is a democratic body, in which the executive (and the magazine staff) are responsible to the membership. I am not suggesting that all organisations for the disabled ought to be democratic in exactly the same way, but it does seem to me that some of them might learn a lot from study of how the Disabled Drivers Association conducts its affairs.

Comment – Spring 1967¹⁹⁷

Success! My rhetorical hope in the first 'Comment' that readers would let me have their reactions to what I wrote actually produced three letters. Paul Driver's pithy response appears on a page of this issue¹⁹⁸. Dudley Kitching¹⁹⁹, also in a letter to the Editor, paid me the extravagant compliment of calling me the Cassandra²⁰⁰ of the **Cheshire Smile**. And Sheila Ridley wrote²⁰¹ to say that while she agreed in principle with what I said in the first article, she thought it quite unrealistic to assume that

'all adult physically handicapped people have a burning desire for self-determination. This, however much we may regret it, is just not so. The majority are content to hand over responsibility, even in the smallest matters. to others'

Miss Ridley went on to make second point:

'It would be nice to know how many members of Cheshire Homes Committees will read your articles; how many residents even. I have an uneasy suspicion that you will be preaching largely to the converted'.

Miss Ridley's remarks have forced me to try to sort out some of the attitudes and assumptions that underlie what I write. I don't think I do assume, as she suggests, that the disabled all hunger for self-determination. If this were the case, perhaps I shouldn't feel the need to write as I do. I believe that people who are physically handicapped are a cross-section of humanity, and, as such, have the full range of attitudes towards life. In each of us, disabled or not, there is the same inevitable life-long tension between our growth towards maturity and the pull backwards towards childish irresponsibility.

For people who are sick or severely disabled this pull backwards can be very strong. It's all too easy for us to regress to a state of unhealthy psychological dependence on other people. Our disabilities often bring

with them a chronic lack of energy which encourages apathy. Being physically inactive may deprive us of a whole world of stimulating and maturing experiences in marriage and family life, at work, and in many sport and leisure activities. Probably, we cannot provide and plan for ourselves and our families the basic necessities of life, and we may lack the opportunity and much of the incentive to strive for a higher standard of living. The scope of opportunities to serve the community in politics or voluntary work may be severely limited. We miss the good side of keeping up with the Jones's – the pressure to maintain expected standards of independence and personal responsibility. And, faced with our physical, economic, and social dependence on them, the non-disabled may try to shelter us, and sometimes also to dominate us.

These are just **some** of the factors tending to make or keep the severely disabled immature. They apply both when people live at home and when they are in an institution. But in most Homes and hospitals there is a further series of pressures towards immaturity. The need to provide centrally so many services and daily necessities deprives the residents or patients of important areas of choice, and denies them expression of a multitude of individual preferences that people in their own homes take for granted. All authority and responsibility is concentrated in the hands of the staff, while the inmates simply have to keep smiling and do as they are told (or asked, in the better class of establishment). The people in all 'total institutions', as the American sociologist Erving Goffman calls them, live out practically the whole of their lives under one bureaucratic authority. It is well known that these and other factors often produce people who are apathetic, uninterested in self-determination and personal responsibility, content (if only at some levels) to let others direct their lives.

It may be objected that maturity is in the last resort a matter of the quality of an individual's mind and spirit. I think this is true in some sense; but it is no reason to underestimate the vital role played by environment and opportunity. It might also be objected that many people are oppressed by the pace and demands of modern society, and that they would welcome a situation in which someone else had to do the deciding. The best answer to that is an invitation to try it – not just for a while, but permanently. A third objection might be that many people who have had all the opportunities I've mentioned are not noticeably more mature than others who've been denied them. Again, this is obviously true, but it doesn't invalidate the point I am making here; people learn

and grow and are prodded towards maturity by the everyday experiences of decision-taking and exercise of responsibility which disabled people may miss.

At last, we are back to Miss Ridley's point. I don't assume that all physically handicapped people are passionately anxious to decide things for themselves. In fact, I assume almost the opposite because, as I have been saying, we are subject to so many special enervating factors. What I am trying to do with my 'preaching' is to stimulate whoever bothers to read me – and I hope this includes a few unbelievers, whether residents, staff or voluntary helpers and supporters – to think about disablement and its effects on people, especially in the context of institutional life.

In particular, I hope to suggest in further articles some directions in which the Cheshire Homes can develop to make the most of the fine foundations already laid. One's own home is obviously the best place to be, other things being equal; nobody in their senses would choose to live in the conventional institution given a real alternative. Yet, paradoxically, I believe that some form of community life may provide the best chance for some severely handicapped people to lead satisfying lives. I don't think we have really begun to realise the full potential inherent in institutional living. If we are to do so, it will mean first of all taking a radical look at the whole concept of residential institutions in a modern society.

Comment – Summer 1967²⁰²

There was a fascinating television documentary recently about the fundraising activities of British charities (in the **Scrutiny**²⁰³ series on BBC 1). We were bombarded with facts and figures. Both low- and high-powered organisers talked about difficulties in retaining or increasing their share of the limited supply of funds and voluntary workers. They bemoaned the way any new idea is copied immediately by competitors in the field. They told us once more how easy it is to raise money for cats and dogs and crippled children, how hard for the aged and the mentally sick.

What shocked me, though, especially where the 'human' charities were concerned, was that only once did anyone touch on the question of taste or of ethical issues in 'pushing their product'. The exception was a man from War on Want²⁰⁴ who said his organisation would not go in for sensational or gimmicky ways of raising funds. They had regular supporters who wouldn't approve of that sort of thing. No doubt the other people interviewed weren't all unscrupulous money-grabbers. And obviously in this country public standards set fairly definite limits on what techniques may be used – the extremes of sentimental or sensational publicity would be self-defeating in our relatively sceptical climate of opinion. Nonetheless, there did appear to be a general acceptance on the programme that what really mattered was the amount of money raised, and that the way in which this was done was not important provided it was effective. In other words, the end justified the means.

This is understandable of course. The knowledge that every pound raised will go to help someone in desperate need brings with it strong pressure to use every trick in the book. Finer feelings may be felt to be something of a luxury, a kind of moral indulgence. What does it matter if you give the impression everyone in India is starving and living in the streets, if in the process you can raise enough money to save the life of one more child? What does it matter if the disabled are portrayed as

'poor things', if as result you can produce the cash needed for research and welfare?

I believe the answer must be that it does matter a very great deal. However attractive a 'practical', results-centred approach may seem in some ways, it grossly oversimplifies what is in fact an extremely complex issue with far-reaching implications.

Even in terms of results, of the amount of money raised, the basic assumption – that pity best stimulates generosity – is not necessarily true. It needs testing by research and experiment. And even **if** it is valid in some sense, a great many related questions still have to be asked on practical grounds alone. Does a direct appeal to pity work only for a limited period – do people become immunised after while (as has perhaps happened with Oxfam's starving child adverts)? Is it good business to make the 'customer' feel afraid and unhappy by concentrating on the worst aspects of disablement, for instance – don't you risk a brand image that in the future will produce aversion rather than interest and concern? If you touch an elderly lady's heart in Bournemouth, might you not at the same time be putting off a rich industrialist in Bolton? One can think of dozens of similar queries.

Quite apart from this kind of practical question, some most important moral and psychological issues are also involved. In her classic book on disablement, **Physical Disability: A Psychological Approach**, Beatrice Wright says: 'If (a) project predominantly portrays suffering or succumbing, and minimises the coping possibilities, the dominant emotions aroused will be devaluating pity and/or fear²⁰⁵. She goes on to point out that, whether or not it is effective in making people give generously, such propaganda militates against good relations with people who have disabilities. It is also bad preparation for anyone who might have to cope with disablement themselves in future.

I would add three further points. First, to stress the negative aspects of disablement only is quite simply misleading (as I think is the equally sentimental other side of the coin, an insistence on wonderful will-power and bravery which also, of course, implies the same unspeakable depths having to be conquered). Second, it is not just the eventuality of disablement which the non-disabled are being ill-prepared for, but also sickness and bereavement, old age, depression, anxiety and so on. All these forms of loss are linked, to my mind, and an unbalanced emphasis on the negative side of disability will adversely affect personal and

community attitudes to a wide range of such everyday experiences. So, a part of a very long-term process of education requires that disablement should be presented objectively, as a loss to be mourned and regretted and maybe cursed, but not as a total loss by any means.

The third point is that publicity which concentrates on the negative aspects of disablement will scarcely help the disabled themselves to cope with their problems realistically and determinedly. It is far more likely to confirm in them society's stereotyped 'tragic' view of their situation, and to encourage them to see themselves, and to expect to be treated, as special people, rather than as people who have special difficulties and therefore certain special needs.

I don't think there is really a final answer to the dilemma. For as long as funds have to be raised from the public, there will remain a certain tension between on the one hand the need to present a problem dramatically and in manner which stimulates giving, and on the other hand the need to present it truthfully and in a way which helps rather than hinders psychological adjustment and understanding. The most that can be done, perhaps, is to keep these very important issues in mind, and to try hard to avoid any methods which implicitly devalue or exploit the disabled.

Nothing I have said here detracts for a moment from the immense debt I owe to all those who work and give so generously to help me and people like me. However, I'm sure they will understand if I say that I look forward to the day when some of their efforts on our behalf will no longer have to be undertaken. It seems to me that sometimes the absolute necessity for money raising may get in the way of direct personal contact with the disabled. There is that much less time and energy to spare. And, human beings being what they are, it is in general harder to relate to someone as an equal if one is also engaged in raising funds on his behalf.

I believe that ultimately it is for **the community as a whole** to ensure that its dependent members receive a reasonable income, in a way which best safeguards their dignity and self-respect. This can only mean payment of adequate state allowances as of right, so that those in need will no longer have to hold out their hands for extra financial help. A series of underlying social and psychological needs would then stand a far better chance of being met. And, in my view, we should also have taken a big step towards the creation of truly civilised society.

Comment – Autumn 1967²⁰⁶

'Your articles are too full of abstract theory. You never come down to saying what should actually be done. We all know the theory and accept it. What we need now is to know what to do about it'. After a year of **Comment** this seems to be the main criticism I've heard, and it is perhaps worth discussing at some length.

This distrust of theorising is of course in some ways admirable and very British! Those of us who presume to theorise and write must always beware of creating delightful, consistent worlds of logic and theory which bear absolutely no relation to the realities of life. It is all too easy to spend one's time tinkering with words and ideas, while ignoring a pressing need for immediate action.

So it is tempting to accept this criticism on its own terms, and to try to answer it by setting out here a long list of specific things I believe ought to be done. Certainly there are plenty of them. I'm in favour of having lots of single rooms in the Homes, of keeping units below 35 beds, of avoiding houses that are too far away from civilisation. I believe in paying adequate salaries to staff, in providing them with excellent accommodation, in arranging for them to have special training. I should like to see more community decisions and less Management ones. I'm all for arranging things so that residents can go to bed when they choose. I favour the formation of residents' committees with real responsibilities in the Homes. I should like to see experiments with different forms of community life, perhaps linked with existing Homes and so on.

It can be very useful to discuss particular issues of this kind, and no doubt there will be occasion to do so in future articles. But in fact I don't really accept the criticism that more academic theorising is a waste of time. I don't believe the Cheshire Foundation's theory has been really thought out – or, indeed, that one can ever talk about theory as a sort of finished product in this way. In any organisation there is a need for developing a body of theory, of general principles, of ideas about the

purposes of the organisation and how they can best be fulfilled. To suggest that this theory can ever have been 'done' implies quite unreal divorce between theory and practice. In fact, theory and practice are indissolubly linked together; each has continual need of the other in order to remain creative and balanced. Yet, at the same time, it is essential for the proper development of theory that it is not shackled by the demand for quick and easy solutions to particular problems. Theory needs time in which to grow, needs certain freedom from practical necessities, a degree of autonomy within which to seek above all to understand situations for their own sake, rather than simply as a prelude to action. In the Foundation we have often undervalued the importance of this kind of theory, of speculation and research and exploratory discussion. The astonishing increase in the number of Homes has not been matched by corresponding growth in our understanding of the work we are doing. The original inspiration needs developing and deepening and adapting to the changed conditions of today. After 20 years the Foundation is having to face what are, in a sense, the problems of success. The long-term social and psychological difficulties arising out of the consolidation of the Homes are complex and intractable. They cannot be tackled adequately on a purely intuitive basis, but will need continued careful thought if any real progress is to be made.

One sign of this undervaluing of theory in the Foundation is the widespread impatience with any concern with words and their meanings. One thinks of the debate about the use of the word 'patient'. The alternative word resident is now used widely, but so many people still seem to feel it's all great fuss about nothing. They regard such arguments as pedantic, and fail to see the value of thinking carefully about the language we use. I find it hard to enter into useful discussion with anyone who takes this point of view. Basic to my own understanding of life is a belief that words have an important influence on all our attitudes and actions. In my philosophy, thought, word and deed can never really be separated.

It's pleasing to see that the Williams Committee²⁰⁷ **Report on the Staffing of Residential Establishments** (reviewed elsewhere in this issue²⁰⁸) refers to 'residents' in every instance. This ties up with their determinedly non-medical approach to the question as a whole. They have made the basic distinction between 'patients' in hospital, receiving medical and nursing care and treatment, and 'residents' in Homes who are there primarily to live.

The Committee's Report shows the same sensitivity about words when it comes to discussing the titles by which senior staff should be known.

‘(...) there has been the problem of name by which to refer to the person in charge of Home, or to his deputy and assistants, which does not carry the wrong associations. "Matron", the most usual, is too closely associated with the nursing profession and we are anxious to dissociate the work and qualities of the word, admirable as those are, from those of the "Homemaker". "Warden", although an honourable title in university circles, has an unfortunate connotation in the general mind, and "Superintendent" has too formal and authoritarian a sound... we have been compelled to use the somewhat clumsy terms "those in charge" or "Heads of Homes".

(My own preference, incidentally, is for the term 'Administrator' – though I suppose it depends on what you mean by administration).

Far from being pedantic, this kind of care over language suggests that certain important new insights are struggling to find expression. Where people feel that an old terminology no longer quite satisfies them, often there is a creative process taking place, a deepening of understanding of a situation or problem. 'Theories' are emerging which will help to shape the future. We should never make the mistake of underestimating their importance.

Comment – Winter 1967

Second Thoughts on Williams

When I first read **Caring for People, the Williams Committee Report on the Staffing of Residential Establishments**, I thought it excellent. After reading it again twice, and attending a Conference on it, I've been having second thoughts, at least about its application to Homes for the physically handicapped. The Committee's main recommendations, for formal training and improved conditions for staff, will be strongly endorsed by most people. The Report provides many interesting statistics and much valuable information. There are plenty of well-intentioned phrases to show that the Committee's heart is in the right place. Their liberal, progressive approach may appear almost revolutionary when compared with the attitudes and policies still prevailing in so many institutions. For all these reasons, and because it is the first broad look at the subject in this country, the Report is to be welcomed.

Despite its undoubted merits, however, it must be said that this is not a very inspiring or carefully argued document. For example, the Committee's basic act of faith in one profession for residential work, to cover all types of Homes, shapes the whole of the Report. Yet the arguments for and against this view, the implications, and the alternatives, are not set out fully. Again, the division of staff into 'care staff' and 'others', the advisability of which might well be disputed, is never properly discussed or justified.

The Committee's analysis of the situation in general leaves much to be desired, perhaps chiefly because of an evident lack of any close knowledge of what it is like to live or work in a residential Home. The Report mentions the need for more 'consumer research', yet the Committee themselves apparently made no attempt to get the views of any residents on the subject at hand. And they give the impression that most of their contact was with senior rather than junior staff.

One important failing of the Report is that it never really comes to grips with the crucial question of the attitudes and motivations of those who enter residential work. No doubt the Committee was anxious to avoid giving offence by delving too deeply into the problems of inadequate or 'bad' staff, or of the less desirable attributes even of the best. This is understandable, but it is unfortunate, to say the least. The difficulties that inevitably arise when one group of people is dependent on another must feature prominently in any realistic discussion and plan for the future.

This omission probably accounts in part for a further one. The Report refers to the opposition between on the one hand the preference and need of many residents for small Homes, and on the other hand the advantage of improved working conditions for staff in most larger Homes. But it is apparently not realised that this conflict of interests extends throughout almost every aspect of an institution's life, quite apart from the inherent tension between staff and resident groupings. The failure to take account of such forces at work is a serious one, and gives an impression of naive optimism about the prospects for easily producing 'harmonious' groups and communities. The Report could have done with some of the sophisticated understanding of the dynamics of total institutions shown by Erving Goffman in his book **Asylums**.

Also missing from the Committee's analysis of the situation, is the vital factor of the stigma and devaluation as persons suffered by most inmates of residential establishments. This stigma stems firstly from the fact that residents are old, or physically or mentally handicapped, or similarly abnormal; and secondly from the fact that they live in an institution. The consequences of the stigma directly condition the work and roles of staff, and it is strange that the Report does not even mention them.

When it comes to the discussion of training there are some surprising omissions too. Evidently quite unrealised are the dilemmas created by the need for practical and in-service training for staff, to supplement and complement the more academic training. Yet there can be a very real opposition between the trainees' needs and those of the residents. Using residents as practice material and to provide training situations for staff may well be detrimental to the best interests of the residents concerned. This problem should have been considered at length.

A second major shortcoming in the training recommendations concerns the reference to the need for attention to be given to ethical and religious

issues. This is conceived of only in the narrow sense of teaching respect for people's religious beliefs and practices, and the application of such ideas as honesty and fairness in an institutional setting. Important as these issues are, it is essential that ethics should be considered on a much wider basis. Staff need to learn about residents' human and legal rights, about the dangers of having people in their power in an institutional context, and about the many subtle ethical problems that arise from this situation.

All these omissions and inadequacies are almost incidental, however, besides what I regard as the central failure of the Williams Report. At no stage does it really question conventional assumptions about residential institutions in our society. It envisages no new forms of communal life at all, although experiments with quite different arrangements for those 'in care' are clearly necessary. And it places nothing like enough emphasis on the need for radical changes in the way most Homes are structured and run. The Committee's one idea seems to be to move from authoritarian to benevolent paternalistic regimes, with no internal changes of structure, and always within the framework of the usual types of institution.

The Report curtseys briefly in the direction of the therapeutic community idea. But there is little evidence that it is taken at all seriously. A better guide to the Report's basic assumptions may be the following two sentences. Talking of members of Management Committees, it says: 'Their role is to provide disinterested concern, unbiased judgement and a sense of perspective brought into the Home from the wider world outside.' And of the staff: 'The appeal of this work consists largely in the opportunity it gives to humane and compassionate people to take responsibility for those in need of care'. Is it extreme to see here attitudes derived from our colonial past, from the bearing of the white man's burden? Perhaps this is a little unfair, and it may be argued that motives are of little importance compared with the essential willingness simply to help people. But the Committee themselves show they have glimmerings of another, better, approach when, in particularly happy phrase, they refer to the staff's work as 'sustaining personality', and again when they mention the desirability of "'care' becoming a joint exercise between staff and residents".

If only the implications of these words had been fully worked out and had informed the Report as a whole. They are directly relevant to the

question of recruiting and retaining suitable staff. An authoritarian or paternalistic atmosphere, with rigid hierarchical structures and 'absolute' power vested in one or two people at the top, where complaints are discouraged and there is no appeal against authority's decisions, where residents and junior members of staff are not expected to participate in the running except in menial capacities, and where there is no realisation of the staff's work as anything other than custodial and dead-end – these are major reasons why many able people are not attracted to residential work or leave it soon after they enter.

No doubt the provision of suitable training, better conditions and higher salaries for staff will in time help to effect the necessary changes. But I don't think we can afford to wait that long. I believe we must urgently set about reforming and restructuring our residential institutions, bringing them into closer relation with modern society and its ideas. More than anything else staff need an enlightened policy and leadership, a feeling that their work is genuinely constructive and in the forefront of modern achievements in the field of social reform and renewal. It is pity that the Williams Committee Report, despite its solid virtues, has not managed to provide us with the imaginative blueprint for the future that we really need.

Comment – Spring 1968

Designing for the Disabled by Selwyn Goldsmith²⁰⁹

If any Cheshire Home Management Committee spends £3. 10s. 0. on Selwyn Goldsmith's²¹⁰ beautifully produced manual, I confidently predict they will save far more than this amount on the first building project they undertake with its help. They won't exactly be able to do an architect out of job. But they will be able to keep up better with one on a major project, and direct the builder with far more confidence on smaller ones.

The revised and expanded second edition of this book is so clearly written and set out that it makes sense of technical architectural matters even to the complete layman like me. It deals with virtually every aspect of design for the disabled, from simple gadgets and the height of door handles, to the layout of streets, offices, and shops. The sections specifically on Homes for the disabled are small, but a wealth of relevant information is available by cross-reference to other parts of the manual. Windows, doors, sinks, toilets, ramps, floors all are dealt with exhaustively, with diagrams, notes, and selected details of costs and manufacturers. The glossary of medical terms and the publications list are useful too. I won't continue labouring the point. For its technical information alone, this is an indispensable book for anyone who has to do either with building or with the disabled. Fascinating and invaluable as all the technical information is, though, for me the most important part of this manual is the 40,000-word Commentary, in which Selwyn Goldsmith investigates the social, psychological and philosophical implications of disability as they relate to design problems. Since publication of the original edition in 1963, he has done a lot of interesting field work, and has revised many of his own ideas and assumptions. The result is probably the most sophisticated and original piece of writing about physical disability yet to appear in this country.

The first edition of **Designing for the Disabled** accepted the orthodox doctrine that the disabled are not really very different from the normal population, and that buildings planned to enable them to manage

independently are also more convenient for everyone else. Most publications in the field still accept these assumptions. This applies particularly in America, where there is strong opposition to any idea of special facilities for the disabled; the ordinary facilities must simply be made useable by the disabled²¹¹. At first sight this is an attractive idea. We are all supposed to want integration with the rest of society, and to be treated as normally as possible. In the current edition of his manual, however, Selwyn Goldsmith completely demolishes this line of thinking. He shows that the attempt to accommodate all the disabled as part of the normal population must often be unsuccessful for both practical and economic reasons; and he contends that it is also based on unsound psychological and philosophical assumptions.

Instead of an unrealistic 'independence' criterion, geared to the very small number of independent wheelchair users of public buildings, Mr. Goldsmith argues that architects should aim at 'usability', which allows for some situations where help may be needed, and takes account of the many 'dependent' disabled people – like most of us in Cheshire Homes. He also insists that often the handicaps experienced by the disabled in their use of buildings can best be overcome by providing special facilities designed for their particular needs. These should complement provisions made for the general public, and should be clearly indicated by signs. There need be nothing stigmatising about such facilities; they simply recognize facts, and their whole purpose is to enable the largest possible number of disabled people to use buildings as freely as anyone else. The main lines of this argument seem to me to be undeniable. And our acceptance of the unsentimental thinking behind it is important, not simply where accessibility to buildings is concerned, but also for the whole future of the disabled in society.

There is not enough space here to do justice to Selwyn Goldsmith's many subtle and far-reaching ideas. He covers an astonishing amount of ground under headings like: The wheelchair population; Social and economic influences; 'Privileged' disabilities; Community attitudes; The inferior status of disabled people; The merits of normality; Adjustment; The recognition of limitations; The merits of dependence; and so on. Many of the points made are relevant to the current debate in the Cheshire Foundation about our aims and purposes (see the Editorial on page 3)²¹². Listen to this, for instance:

'The attitudes which characterise disabled people who have been successfully rehabilitated and have adjusted to their disability [is a] realistic acceptance of the disability and what it involves, subordination of normality goals and physique values, willingness to ask for and accept help in situations where help is necessary, and the recognition of the value of dependence as well as of independence have direct relevance to the establishment by the architect of optimal design criteria'

Most of us would want to add to, or subtract from, such list of the attitudes exhibited by 'well-adjusted' disabled people. But the passage shows the way in which Mr. Goldsmith refuses to isolate strictly technical factors from human ones, and by doing so manages to raise issues of importance in a field much wider than that of design.

There are places in **Designing for the Disabled** where Mr. Goldsmith's challenging approach leads him to minimise difficulties and counterarguments. For example, I believe as strongly as he does that an unambiguous pictorial sign indicating the presence of suitable facilities for wheelchairs in shops, restaurants and so on, is a psychologically sound proposal which could produce nothing but good if it was implemented. But having seen the embarrassed looks on the faces of customers in such places when the disabled arrive, and knowing of instances when disabled people have even been refused admission, I can't help wondering how many restaurant owners, say, would like to advertise that the disabled were welcome on their premises. A number of people feel acutely uncomfortable in the presence of disability or deformity, and most of us would on the whole prefer to avoid them if we can do so without making it too obvious. This applies particularly when we are out 'having a good time'.

Again, I am not sure that I fully share Mr. Goldsmith's enthusiasm for the idea of being carried up and down flights of stairs in a wheelchair in order to attend lectures at university. Nor do I go quite such a bundle on the delights of dependency, though I agree that independence at all costs is a disastrous attitude. But these are minor quibbles. Indeed, Mr. Goldsmith himself recognises the need for more research and discussion on the points he raises.

The important thing is that here is first-class mind engaged in rigorous analysis of the factors affecting one vital area of the lives of the physically disabled. After reading this manual, I for one will never again be quite so eager to generalise from my own experience. And in future when I talk gaily about the need to eliminate architectural barriers, I shall have rather more idea of the importance and complexity of some of the issues lying behind this catchphrase.

Comment – Summer 1968

Disabled Power?

My intention this time was to have used the available space to put the case for single rooms in residential Homes. But I've just received the Spring issue of **The Magic Carpet**, quarterly magazine of the Disabled Drivers' Association, and it contains two items of such importance that I want to draw attention to them immediately. So, my impassioned plea for single rooms must wait awhile.

The first **Magic Carpet** piece to arouse my interest was a long article by Selwyn Goldsmith (whose highly commended architectural manual, 'Designing for the Disabled', I discussed in the last Comment). In his usual forceful and entertaining manner, he pitches into Stirling Moss²¹³, who has been advocating the provision of adapted cars for the disabled instead of the present invalid tricycle²¹⁴. Mr. Moss apparently believes that the Ministry of Health tricycle is 'anachronistic, hazardous to drive, and debases those who use it'. Mr. Goldsmith doesn't seem to be against the provision of cars in certain cases, but he shows that many of Stirling Moss's arguments are based on a sentimental, unrealistic, and even neurotic view of disablement. He is particularly severe on Mr. Moss's assumption that pride is the chief motivating force in many disabled people's lives, and in the process displays his formidable knowledge of the complex social and psychological aspects of disability. This is controversy at its best.

Towards the end of his article, Selwyn Goldsmith says: 'One of the reasons why, by contrast with disabled drivers, those people who are more severely handicapped are underprivileged is that they do not comprise an efficient pressure group capable of challenging the inadequacies of existing services in an effective fashion'. This links up very much with the second interesting **Magic Carpet** article, which I think puts forward an idea of considerable value.

Nigel Harvey²¹⁵, who says he joined the Disabled Drivers' Association as a driving enthusiast in 1965, now feels that the time has come for a change of name for the organisation. He suggests calling it the Disabled Citizens' Association, and says this would be more in line with the actual interests and activities of many members. Apparently large number of D.D.A. members do not drive, and join primarily for the social life afforded by the local Groups. And there has been recent shift of emphasis in D.D.A. policy towards tackling things like employment and welfare difficulties.

Mr. Harvey points out the need for a national organisation for the disabled. He suggests that all the associations for particular disabilities and problems, while doing excellent work, do not adequately represent the interests of the disabled population as whole. He says:

'Membership of the D.D.A. has probably demonstrated to most of us that we have far more needs in common than the multitude of 'special' charities would indicate to the casual observer. The inevitable duplication of effort, lack of coordination in aims and policies, and absence of united representative voice, are all functions of their introvert nature'.

In Mr. Harvey's view another argument for a new Disabled Citizens' Association is the 'shocking lack of uniformity in the provision of appliances and other aids for the disabled'. He believes it is in fact more of a lottery than a service, and thinks handicapped people need far more information and advice in order to make proper use of the help available.

Mr. Harvey feels that the Disabled Drivers' Association is the group best fitted to evolve into the national organisation he envisages. The D.D.A.'s extremely vigorous campaign for the issue of cars instead of tricycles seems to be nearing fruition. Now they should be able to take up a variety of new causes with the same skill and enthusiasm, and also provide a platform for fresh ideas and policies in the whole field of disability. To do this they must change their name and their image, and must recruit many more members²¹⁶.

I would strongly endorse Mr. Harvey's main points, having long felt the need for a more militant organisation for the disabled, and particularly one which is sensitive to the changing needs and wishes of its members. The Disablement Income Group is undoubtedly a model in both these respects. Yet their last A.G.M. showed they are faced with a crucial

dilemma, which points again to the need for a more comprehensive organisation. Should they stick single-mindedly to their main task, the obtaining of a proper pension for disablement? Or should they risk blunting the edge of their campaign by taking up the large number of social welfare issues that have presented themselves and urgently require ventilation and action?

It may be felt that the Central Council for the Disabled is giving the national leadership required, and that it provides an information service and coordinates the activities of the various voluntary societies. While I fully appreciate the efforts being made by the Council, my impression is that they are not very effective and, perhaps more important, that the disabled do not in general regard it as their organisation. How many of us attend the conferences arranged, or sit on the various committees, for instance?

What we really need, I believe, is a rather more awkward and less respectable national Association, run primarily by the disabled themselves. For many of the same reasons as Mr. Harvey I feel that until there is something of the kind we cannot conduct our affairs properly in three important respects.

Firstly, we need democratic organisation for continuing discussion of the many issues raised by disablement; for carrying out **Which?**²¹⁷-type consumer research; and for ensuring that relevant up-to-date information reaches as many disabled people and their helpers as possible. Secondly, instead of the present uncoordinated, inefficient, and unjust scramble for government and voluntary resources. we need the machinery to decide amongst ourselves what is the fairest order of priorities, and then to organise and campaign together so as to bring pressure to bear where it is most effective. And thirdly, we need to enlist the talents and efforts of the 'privileged' disabled, as Mr. Goldsmith calls them, on behalf of those less able to assert their rights for themselves – the ones who live in institutions, for instance.

Of course, not every disabled person would, or necessarily should, want to join such a 'trade union', and certainly I for one would not be keen on the social activities side of things. It seems to me, however, that one form of neurotic reaction to disablement is a refusal to identify at all with others who are similarly placed. The disabled do have certain things in common though they are perhaps not the things many people imagine. Recognition of one's membership of this sub-group in society,

and a willingness to offer one's talents to it to some degree, however limited, are perhaps two of the elements in healthy response to disablement. Neither the man who refuses to mix with other 'cripples' on principle, nor the one who is only happy in their company, can be said to have adjusted properly to his condition.

The creation of a national association which we could be proud to call our own – that is, one clearly playing a vital part in improving the quality of many disabled people's lives – could also help some of us towards making a better personal adjustment. At the moment a lot of the disabled are put off by the paternalistic, 'outings for the poor things' image of so many organisations, while those who do join them often seem to assume a purely receptive and dependent role. Both groups might be helped to come to grips more satisfactorily with their situation if there was a forum for unsentimental discussion of common needs and aspirations, with a view to taking vigorous action on both a local and a national basis. If our meeting together as disabled people was more often at this sort of adult, purposeful level, with the tea-and-buns aspect arising only incidentally, I believe we should be making a major contribution both to our own rehabilitation and to the education of society as whole. You can count me in, Mr. Harvey.

Comment – Spring 1969

How to Succeed in Rehabilitation....²¹⁸

My instinct is to avoid the word 'rehabilitation' in connection with the work of the Cheshire Homes. For one thing, I'm wary of the medical implications. 'Rehabilitation' conjures up nightmares of knife-happy orthopaedic surgeons and muscular physiotherapists imposing treatment on some unfortunate patient, and I wilt at the thought.

No doubt my visions haven't much to do with reality. But certainly until recently I felt that rehabilitation theory and techniques had little application to residential Homes. Now I'm not so sure, especially since reading the final article in an American book called **Psychological Practices with the Physically Disabled** (Garrett and Levine eds. Columbia UP. 1962)²¹⁹.

The author of this particular article, Dr. Franklin C. Shontz²²⁰, takes as his subject psychological aspects of **Severe Chronic Illness**. He discusses the meaning of descriptions like 'chronic illness' and 'severe disability', and insists on distinguishing between terms which classify diseases and terms which classify people. He goes on to deal most perceptively with various rehabilitation issues, including a useful summary of the main psychological reactions to severe disablement.

In the space at my disposal, I want to discuss just one aspect of Dr. Shontz's article. He points out that in the early days of rehabilitation, when patients could usually expect to return to work and to live at home, there were few problems about the all-important question of motivation. Both society and the patient himself were clear that it was desirable economically, socially, and psychologically for him to be rehabilitated so as to return to productive work and life at home. Society obviously stood to gain economically in particular. Thus, the patient not only usually wanted to return home and start work so as to regain his self-respect, but he had the warm approval of society to urge him on.

As rehabilitation services have expanded, however, to include those who may not be able to go home to live independently and earn a living, the question of motivation has become much more difficult. As far as society is concerned it still makes a certain economic sense for a severely disabled person to be helped to live as independently as possible. This is in any case now accepted as a rehabilitation goal even when there is no likelihood of a return to normal life. However, for the patient himself:

'.... the motivating forces he perceives are frequently only the negative ones associated with **becoming less burdensome** to a community. Society grants no special acknowledgement of gratitude to the person who manages to live without an attendant or who learns to care for his skin so as to free his physicians' or nurses' time. The patient himself does not get any money because he saves it for society.... not being a burden is different from being a help and not getting worse seldom offers the same kind of satisfaction as getting better'

Dr. Shontz's insights will strike a chord in anyone who has ever thought about the situation of people in residential Homes. There is ample evidence that society does not really expect the severely disabled, and particularly those in institutions, to contribute anything of real importance or to lead independent lives. There is consequently a loss of the pressures and incentives which in rehabilitation should lead to the maximum reasonable degree of physical, economic, and psychological independence. Some residents may have the personal resources to overcome such a lack of external stimulus, but inevitably many others tend to become apathetic.

Given this situation, I believe it is desirable for the Cheshire Homes to mount some form of countervailing 'rehabilitation' programme, utilising whatever positive motivating forces we can discover²²¹. My main proviso is that great care must be taken to safeguard both the person's right to opt out of any programme and, if he does participate, his right to share in all the decision-making processes involved. As long as these two basic rights are genuinely safeguarded, it seems to me legitimate to encourage people in institutions to live as actively and independently as possible. One may argue about the merits of particular programmes and proposals. But as a general proposition it appears to be true that most

people are happier and more fulfilled, and can cope with their disabilities better, if they are as independent as is realistic for them, if they have useful work to do, are involved in varying activities and decisions, and feel that others depend on them to some degree.

Of considerable importance here is the difference between **opting out of** and **opting in to** a rehabilitation programme. The life of someone in a residential Home is influenced profoundly by the prevailing ideas and attitudes about dependence and independence. If the atmosphere of the Home stimulates residents to use their abilities to the full, it should still be possible to guarantee the right of non-conformists to **opt out** if they choose to do so. But I do not think the reverse holds good. In an atmosphere which tends to encourage dependency and apathy, if only by default, it is nothing like so easy for residents to **opt in to** a more active life – even if in theory the opportunities are there. Indeed, it takes quite exceptional qualities to combat an unstimulating institutional environment over a long period.

If we do accept the need for some positive programme to help residents in Homes to realise their potentialities and avoid stagnation, how then do we tackle the question of motivation which we have seen is so crucial? In his article Dr. Shontz doesn't pretend there are any easy answers. But he says: 'What the chronically ill person needs in order to succeed in rehabilitation is a positive reason for living that is not premised upon his financial value either to himself or to society'. And, fortunately, 'the positive values of life are certainly not necessarily tied entirely to the physical aspects of existence'.

So, it seems that the severely disabled (like everyone else) need to find some sort of meaning in life or reason for living, and that for them this must probably contain a larger element than usual of non-physical and non-economic justification. Most of us will perhaps accept the rather obvious truth of this generalisation – even if we vary in our estimates of how realistic it is to hope that such a sense of purpose can in fact be achieved. But it is necessary I think to make a careful distinction here between two kinds of meaning or purpose. The first kind may be called 'ultimate' – by which I mean religious and philosophical opinions and beliefs. The second kind are the limited 'reasons for living' that most people find in everyday life – in personal relations, in work, in leisure activities.

No rehabilitation programme, whether inside or outside the Cheshire Homes, should be concerned with these 'ultimate' meanings (despite some of the odd statements about 'spiritual rehabilitation' by Management Committee members at the 1967 Annual Conference²²²). Clearly it must be an impertinence to try to foist particular religious or philosophical beliefs on people who simply happen to be more captive than the ordinary citizen. The difficulty comes, of course, when the implicit or explicit moral assumptions and scale of values of those 'in charge' are imposed – since these tend to have an ultimate or absolute character. This is to some extent an unavoidable dilemma which needs treatment at length if its implications are to be explored adequately. For the present discussion the crude distinction between an ultimate and an everyday sense of purpose is useful and will have to suffice.

It seems to me that the Cheshire Homes should concern themselves exclusively with the second 'everyday' category of meanings, values, purposes. Plainly they cannot presume to give residents any sort of purpose in life just like that. But, in my experience, it **is** possible to do something towards creating conditions in which even the most severely disabled people may gain or retain a feeling that they matter and that what they do is important. It is a slow, difficult, and complex business in the context of institutional life and when severe disability is present. It is always to be expected too that some people will reject both the opportunities offered and the underlying assumption – that life is still worth living to the full no matter how disabled one is. Clearly people have the right to disagree, to reject offers of help, and to believe their lives are pointless if they choose to do so.

Before anyone condemns those who do 'give up' in this way he should remember two things. First, the prevailing attitudes and beliefs in society suggest that for the severely disabled life is **not** in fact worth living, so the burden of proof lies with anyone who maintains otherwise. And second, none of us can ever be sure that we ourselves would be able to cope with someone else's situation. This does not mean assuming a pitying, sentimental attitude towards them. But it does mean that efforts at rehabilitation should never involve exhortation or a moralistic approach. It means also that great care should be taken not to reject or devalue residents who become passive or depressed, or aggressively non-conformist, whether from choice or because of their type of disability or personality.

If it is to be successful any rehabilitation programme within Cheshire Homes will need more specific objectives than have been mentioned so far. Here Dr. Shontz has a few further hints which may be of use. Writing of the factors that usually motivate rehabilitation he says: 'Socially recognised work, a paycheck, self-respect, contact with those who understand, a feeling of involvement in something personally valuable and important, a sense of growing mastery – all represent **positive** gains from the patient's point of view'.

Here we have the challenge. We are faced with society's unhelpful assumptions about severe disablement. Probably we cannot offer that steady progression back to life in society which is the chief satisfaction normally afforded by rehabilitation. We have to contend with the depressing and enervating effects of severe – sometimes increasing – handicap, and with the pressures of permanent institutional life towards inertia and irresponsibility. Yet despite all this we have to try to produce a stimulating environment which will offer residents some of the positive satisfactions and incentives that Dr. Shontz has detailed.

It is my belief that only the application of a wide range of measures, many of which may have painful, even revolutionary, consequences for management, staff, and residents, stands a chance of engaging the underlying problems. Personal and communal growth cannot come without change and upheaval. The ways in which an institution is structured, and run are perhaps the most important of the factors to be considered, partly because they are relatively amenable to change, but above all because they have such a crucial effect on the quality of the lives lived by residents. No amount of trips to the seaside, entertainments, physiotherapy, occupational therapy, or medical and nursing care (at least as these are commonly understood) can for most people go any way towards giving 'reason for living'. Perhaps nothing can, for some. But for many others a sense of purpose in daily life may emerge gradually from dynamic policy of helping them to assume maximum responsibility for the direction of their own lives both individually and collectively. This is the sort of rehabilitation with which the Cheshire Homes should concern themselves.

Probably it is impossible for any institution to provide adequate substitutes for the satisfactions and sense of purpose gained ideally through family, work, and leisure situations in society as a whole. But residential Homes can only avoid complacency by constantly measuring

themselves against this ambitious aim. At least if they do pursue a policy of actively encouraging residents' initiative and self-determination, this should result in increased contacts with the world outside – particularly, one hopes, in the field of employment. And ultimately, perhaps, it is possible to see this kind of rehabilitation leading to the development of rather better ways of helping some disabled people than the residential institution as we know it today.

Section 5: Writings on the Disablement Income Group (DIG)

While most disabled people lived outside of specialist Homes or hospitals, these two types of facilities were at first the focus of public interest in disabled people's disenfranchisement. Partly, this was because disabled people weren't the only people locked up in them; older people and people with mental distress were already recognised by as groups who were hard done by, and a lot of interest in disability came about simply because disabled people shared the same living conditions. Perhaps more importantly, however, institutions were one of the few cases where you could meaningfully discuss what kind of support disabled people should expect and who was responsible for providing it. The law was clear: local councils had to sort out somewhere to live for people who weren't managing in the community, and they could use charities or hospitals to provide it. While protesting how these institutions worked was never easy, it was at least straightforward that charities, hospital managers and local councils were responsible for them working the way that they did, and had the power to change things if enough pressure was put on them.

For disabled people living outside institutions, the question of what support they should get, and from whom, was much more complicated. Local and national government didn't have a single understanding of 'disabled person' which gave someone access to extra support. The support that existed was mostly built around either types of impairments (particularly sight-loss or hearing-loss) or, more commonly, **how** somebody got their impairment – with people injured in the military or through their work enjoying more rights than somebody born with an

impairment, or someone who got one through illness or an accident at home.

This inequality was clearest, and most ridiculous, in the benefits system. Someone who was impaired through work or injured in the war was entitled to a pension close to the average wage, but somebody with the exact same impairment through another way was in a very different position. For these people, their only entitlements were to the same unemployment benefits as non-disabled people (which were set deliberately low to encourage people back into work), and a tiny top-up benefit called National Assistance, often hated by people who claimed it. Instead of being run through the government's Department of Social Security like other benefits, National Assistance was handed out by panels of local civil servants and respected citizens. It was left up to them who should or shouldn't get a pay-out, so applying for it felt like begging.

Sexism made the situation even worse for disabled women. Benefits were often topped up depending on how much tax a person had paid. As women were discriminated against in work, they were often only paid a pitiful amount and consequently hadn't paid much Income Tax. If they were married, or living with a male partner, they were entitled to nothing at all. The ideas of the time ran that it was a man's job, not the government's, to provide for his family. Married disabled women (or 'housewives' as they were patronisingly called) not only had no financial independence, but the whole household was often forced into poverty as husbands and boyfriends quit jobs or cut their hours to support their partners.

Disabled campaigners and some politicians had realised in the 1940s-and-50s that the benefits system caused widespread poverty amongst disabled people, but campaigns around benefits had fizzled out and the government never saw reforming the system as a priority. It wasn't until 1965 that two very talented disabled women, Megan Du Boisson and Berit

Moore (later Thornberry after remarriage), started a powerful organisation fighting against disabled people's poverty. The Disablement Income Group (DIG) demanded, from its outset, that benefit payments to disabled people should have nothing to do with either their gender or how they got their impairment, and should not prevent them from getting whatever kind of work was accessible to them. DIG envisaged a National Disability Income (NDI) which would bring all disabled people's incomes in line with that paid to people with work-related injuries, end their reliance on National Assistance, and pay for their extra-costs for specialist equipment or services.

DIG took off quickly and was exciting for a lot of disabled people who'd been denied any kind of voice in public life. Part of DIG's strategy from its beginning was to get support from across society, so membership was open to disabled people and set at a price they could afford. Although more non-disabled than disabled people joined DIG, there was suddenly an organisation publicly talking about disability and injustice, which was fronted by a disabled woman in Du Boisson, and which any disabled person could join as an equal member to anyone else. What's more, Du Boisson and some other DIG leaders were personally committed to disabled people having a real democratic say in how DIG worked; Du Boisson was in constant contact with disabled members around the country, and was keen to use their ideas and experiences to make the campaign more effective. In its early days, this meant that DIG was also open to addressing issues that weren't simply about benefits and incomes if they were raised by disabled members – including supporting campaigns around mobility, personal assistance, and housing.

Another part of DIG's strategy, however, prevented it from becoming a truly democratic disability organisation. Du Boisson and Moore had figured out early on that a National Disability Income could easily fit into the political programs of all the major parliamentary parties. For the Labour Party, it could be framed as making the welfare state solve one more problem of

poverty and, basically, as the type of thing Labour was committed to doing anyway. For Tory and Liberal MPs, whose ideas on welfare were based on separating the deserving from the undeserving poor and not increasing the size of the state, the argument could be made in a different way. Disabled people were, in this view, clearly amongst the deserving poor; and providing cash benefits meant that they and their families could pay for support in private marketplaces, rather than the government getting involved to provide expensive services. With what looked like a clear path to the NDI for every party that could form a government, there were reasons for DIG to focus a lot of their energy on talking directly to politicians in Westminster – something that was made easier by MPs from all the major parties, as well as professional researchers and lobbyists, joining DIG in large numbers in its early years.

This raised two problems for disabled people at DIG's grassroots. The first was whether they were actually needed for the campaign to work. To lobby a politician effectively, all you really needed was a handful of insiders in parliament, academics who could write policy papers for them, and a few people who knew how to put eye-catching stories in the newspapers. DIG did organise a couple of large demonstrations, as well as public meetings around the country, but over time it became clear that mobilising the grassroots for these things wasn't as important to DIG's leadership as meetings with government ministers. The second problem was that DIG's strategy in parliament relied on not upsetting anyone who had, or might gain, power. In practice DIG could only campaign on issues that weren't controversial and, more difficult still, had to change their own campaign goals as soon as something they demanded fell out of favour with government.

These contradictions in DIG's strategy weren't obvious to members when things were going well, and while Du Boisson led the Group. By appealing to all kinds of political views, DIG was able to appear regularly in all the major national newspapers – from the conservative **Times of London** to the

communist **Morning Star**. The number of academics and lower-level politicians who gave their skills to DIG made it impossible for Harold Wilson's Labour government to ignore, and its leaders were given access to government Ministers and committees of MPs who planned new laws or regulations around disability issues. Du Boisson took full advantage of these opportunities. She was well-informed, an excellent public speaker, and very politically savvy; she took part in several public debates with Ministers and opposition figures where she tied her opponents in knots without ever picking a fight with them. Du Boisson painted the NDI as an issue of common sense that rose above politics; and herself as a moderate, respectable reformer with a message all decent minded people would agree with. Both Labour and Tory politicians were forced to say in public that they were sympathetic to her arguments, although behind closed doors they were a good deal less complementary. From the grassroots, it looked like DIG were close to getting the NDI, and Du Boisson's efforts to stay in touch with disabled members meant those who didn't spend their days meeting politicians felt like they were still part of a movement.

In 1969, everything stopped going well. Du Boisson tragically died in a car crash on her way to DIG's national conference, and it soon became clear that she was impossible to replace. While DIG elected highly professional disabled people to be its spokesperson after her death, these all came from the professional middle classes and had neither the communication skills nor the level of trust from the grassroots that Du Boisson had built up. Making things worse, it became obvious that, for all the fine words of Labour and Tory politicians, neither party was going to pursue the NDI in government. Using pressure from the public and parliament's backbenches, DIG helped force Wilson's government to accept that there should be some extra benefit to pay for personal assistance; but the amount didn't cover the costs of hiring a home help, wouldn't be paid out to everyone who needed support, and did nothing to address disabled people's poverty overall. When the Tories

were elected in 1970, disability benefits were not a real priority, and the economic crisis of 1973 pushed the idea even further from their minds.

Everyone in DIG guessed, correctly, that the days of a government flirting with the idea of a universal income were over; but they disagreed over what that meant for them. A large section of the leadership argued that DIG needed to change its demands. They believed that you could still get some kind of improved benefit out of the Tory government using the strategy DIG had used so far, but that DIG had to drop any idea of this being a universal benefit along the lines it had first argued for. They put forward a more modest benefit as their new demand – the Contribution Adjusted National Disability Income (CANDI). This proposal accepted that those who'd never worked would get no extra-income, and that people injured at work or in the Armed Forces would continue to get a better deal than everyone else, but suggested that workers who became impaired part way through their career should get some additional money. Getting CANDI would require all of DIG's efforts, and the constitution was changed to make DIG solely about campaigning to reform the benefits system – rather than an organisation that could campaign on other issues if its members demanded it.

Another section of the leadership, grouped around the academic Peter Townsend and the National Federation of the Blind, believed in a more aggressive carrot-and-stick approach to the government. They also believed that DIG needed to change its demands, but felt that the CANDI proposal went too far. They put forward an alternative, incredibly complicated, proposal for a disability income which was based on the claimant's support needs rather than their work history. By setting this level of need high, and therefore excluding a lot of disabled people from claiming it, this faction believed the government could be made to adopt it as a relatively cheap reform that could be made more generous later (after the economic crisis, and presumably by a more left-wing government). To achieve that, though, this faction believed DIG

needed to stop being respectable and really go out to hammer the government in the media, through street protests, and in its own publications. This group would eventually split away and form the Disability Alliance.

The third response to DIG's crisis is closely linked with Paul Hunt. Hunt had joined DIG early and was, as we see from the writings in this section, a fairly straightforward supporter of its original strategy. Apart from his scepticism about whether a decent income would prevent disabled people being institutionalised²²³, there's very little difference between Hunt's early articles on DIG and its official press-releases or articles by members of its Executive Committee. Hunt's response to the crisis in DIG, however, was to hold this original line much longer than the leadership wanted to. DIG's failure, for Hunt, was not just that it hadn't been prepared to take on politicians more aggressively, although he agreed with Townsend that this was a problem, but that it had built its campaign around them in the first place. By limiting itself to one issue, and by having a campaign which included disabled members less and less as time went on, DIG had basically become a campaigning charity like any other – focussed on a single issue and competing with other disability groups for influence. This made it too dependent on professionals, and unable to chart its own course when the government decided it could do without it²²⁴. The only way around this was for DIG to become both more willing to pick fights, and to place its disabled members at the centre of its strategy – as they, and only they, could properly decide what the priorities for disabled people should be and at what cost these should be pursued.

Hunt continued to believe that the NDI was the only reasonable solution to disabled people's poverty (at least without more radical social changes), and that any group dealing with incomes for disabled people should be pushing for it. DIG's leadership, split on the question of what to replace the NDI with, called a conference in 1973 where Hunt defended the original policy against CANDI and Townsend's benefit scheme. The outcome of this conference probably broke any faith in DIG

he had left. Hunt won the conference vote; the NDI would remain DIG's national policy. DIG's leaders, however, chose to ignore this democratic decision by their members. DIG's constitution, its national publications, and its members might say that the group demanded a proper income for all disabled people, but in reality it was CANDI that DIG's leaders spent all the organisation's time and resources on.

Justice for the Disabled²²⁵ (1967)

The Disablement Income Group was founded in 1965 by two housewives who are themselves disabled by multiple sclerosis, a disease which comes on in adult life, has no known cause or cure, and which produces gradually increasing paralysis. Mrs. Megan Du Boisson and Mrs. Berit Thornberry discovered that, despite their devastating problems, in one respect at least they were fortunate compared to many other disabled people. They both had husbands whose income was above average. To their surprise and dismay, they found that many people not only had to struggle with the unavoidable problems of permanent disablement, but were also living in varying degrees of poverty. They started D.I.G. to try and remedy this situation.

Less than two years later the Disablement Income Group is a nationwide organisation, with a score or more local branches throughout the country and a fast-growing membership, not only of the disabled but of interested friends and supporters too. The Group has received a great deal of publicity through the press, radio, and television, and has the backing of most of the voluntary and professional bodies in the field. Churches and political parties have shown considerable interest and have offered support. D.I.G. is in regular contact with the Ministry of Social Security, and has had interviews with the three Ministers primarily concerned with the welfare of the disabled.

Some of this “success” (the government hasn’t actually **done** anything yet) must be due to the charm and drive of Mrs. Du Boisson, who is now Secretary and has been the moving spirit all along. But D.I.G. also has a very strong case to put. The sort of anomalies and hardships they have discovered and are publicising are startling in a society which prides itself on its Welfare State. It is true that with our network of social security arrangements, National Health Service, Local Authority Health and Welfare Departments and array of voluntary organisations, Britain is one of the best countries in the world in which to be disabled. However,

there is still a very long way to go before all the sick and disabled receive really just and humane treatment. This applies with particular force to the question of pensions and allowances.

If you have ever thought about state financial help for the disabled, you have probably vaguely imagined it must be based on the extent of the handicap, any special needs involved and the number of dependants. It seems a logical idea. But the reality is very different. A great deal depends on the **circumstances** in which the disability first arose. There are various historical “reasons” for this strange state of affairs. For instance, people disabled in war naturally have a strong claim for adequate financial help, and they get it. Also, those injured at work benefit from legislation passed as a result of trade union pressure, and even if totally paralysed can at least expect a reasonable income. A severely disabled man in either group, having a wife and two dependent children, might receive £18 or £20 a week. Unfortunately, these excellent developments have left behind other groups, with just the same requirements when their capacity to work is reduced or lost completely, but who have had no one to press their claims in the past.

If you are a civilian, and your disablement arises other than as a result of your paid work, the state benefits payable to you are likely to be inadequate – to put it mildly. This means that there are many thousands of people and their dependants living in poverty or near poverty simply because they fall into the wrong category. This includes people who have had accidents at home, for example, or have had strokes or heart attacks, contracted diseases like polio, rheumatoid arthritis, or muscular dystrophy, are suffering from a psychiatric illness, or have had physical or mental handicaps at birth or arising in childhood. Nobody knows exactly how many people are living in financial need as a result of these conditions, but the numbers are certainly substantial. D.I.G. and other bodies are trying to produce reliable estimates. Meantime, if the figures don't yet exist, the facts undoubtedly do.

This letter illustrates the quite unnecessary strain that lack of financial help is putting on families with a disabled member. It is from a man whose wife has been practically helpless for five years following a stroke.

“In order to pay my way I have to work at least six hours overtime which means I am away from home eleven hours a day. I have to get up just after 5 a.m. to prepare my wife's mid-day meal and our breakfasts and to get her washed and

dressed and leave the place tidy. I return home at 6.10 p.m. only to start work again. Sometimes I feel I'd like to run out and leave it all behind but the ties are too great. I hope I shall always feel this way²²⁶

This example also highlights the cruellest anomaly in the whole set-up. The disabled housewife often receives **no state benefits at all**, no matter how severe her handicap or how desperate the family's plight. Apparently, women running their homes and bringing up children are not considered to be "gainfully employed", and so are not insurable under state schemes. Unless the housewife happens to be also working outside the home when she becomes disabled, or had been so working less than two years previously, she can claim nothing. If her husband is in employment, she is not even eligible for Supplementary Benefit (formerly National Assistance)²²⁷, however low his income may be. For assessment purposes she is considered solely as an extension of her husband, and no one in full-time work may receive help.

What income there **is** in a home when the wife is severely handicapped has to cover not only the ordinary everyday necessities, but also various special needs. These may include the employment of someone to do the work in the home usually done by the wife herself, payment for any personal attention or nursing she may require, perhaps expenses like a special diet, extra heating, and extra wear on clothing. Even if expenditure on these items is cut to an absolute minimum the strain on an average budget is obviously impossible. The home help and home nursing services provided by local authorities are usually so inadequate as to make no difference in any of the more serious cases.

Faced with this kind of desperate situation some husbands give up work to look after their wives and children, and they all then exist on Supplementary Benefit. Exist is the operative word; with two dependent children, such a family might receive £8 or £10 plus a rent allowance. Other men understandably cannot face such a struggle, so their wives go into a hospital ward (often one for the senile and dying) and the children go into care. Some husbands simply leave altogether. The tragic irony of the whole thing is that the cost of a hospital bed, plus the cost of keeping the children in care, would usually cover several times over what it needs to keep the family together. Of course, a proportion of homes would still break up under the other strains that disablement

brings. But if proper financial help were available, there would be at least a better chance of survival.

Another letter from D.I.G.'s files illustrates a second outstanding anomaly. After thirty years in work, the writer is now unemployed and registered as disabled. His income from Sickness Benefit and allowances is £8 13s, 6d. a week, on which he has to keep himself, his wife and their fourteen-year-old son. The rent alone comes to "2 4s, 5d. He says: "We do not have meat in our family now, we cannot afford it". This family is not even receiving the minimum laid down by the Ministry of Social Security because, like many others, the husband is affected by what is known as the "wage stop". This is a regulation which says that no one can receive more in benefits than the average amount per week he was earning when last in work. It is evidently designed to make sure there is a financial incentive for the unemployed to look for a job. Its application to the long-term sick and disabled only has the effect of penalising them and their dependants most unjustly. The tragic irony of **this** story is that if the man had only happened to become disabled through his work or while in the services, he would be receiving probably **double** the amount now being paid him.

A third group hard-hit by the present system, or rather lack of system, are single men and women. Some who are severely handicapped from birth or in childhood face a lifetime of subsistence on Supplementary Benefit, with no prospect of ever attaining a standard of living anything like that of the majority in this country. The same is true of the single person disabled in adult life. The Sickness Benefit is nothing like enough to live on by itself, so he or she too must have recourse to Supplementary Benefit. If the chance of marriage comes along for anyone in this group, it may mean a complete loss of income. Should either husband or wife go out to work, then any Supplementary Benefit formerly payable ceases immediately. I know of a couple who are living "in sin" because they just could not afford to pay for the help the man needs if his Benefit were stopped. He is almost totally paralysed by polio. Once again, the extraordinary thing is that when the severely disabled live in institutions, the state pays large sums for their maintenance. If they try to lead a more normal life in the community, only a fraction of this money is available.

Lying behind all these anomalies is one crucial point. The category of permanent disablement, as distinct from temporary sickness, has never been administratively recognised. Someone in bed for a week with flu

receives virtually the same benefit as some-one facing a lifetime of total paralysis, or dying slowly of cancer. Yet it is obvious that Sickness Benefit and related allowances are scaled simply to tide over limited periods off work, not for years of disablement. In the short-term, most people can dig into savings or cut down on luxuries to get by. A longer period off work may mean a few debts, or an overdraft at the bank, but these can be put right when things get back to normal. Permanent reliance on state benefits, perhaps with a growing family to cope with, and certainly with many special needs arising out of the disablement, is a very different proposition. It requires very different provision.

The Disablement Income Group is proposing first that this special category or permanent disablement be officially acknowledged. Then there should be a modest basic income related to the degree of handicap, plus allowances according to the number of dependants and for any extra needs – like help with personal care, for instance. This is in fact very much what the industrially disabled receive already. The present Industrial Injuries Assessment Boards could be expanded to do the same job of defining the extent of the handicap and the benefits payable. They could also make sure rehabilitation possibilities had been fully explored, and see that any malingerers were eliminated.

Since no accurate figures for the civilian disabled yet exist, it is difficult to estimate the cost of implementing D.I.G.'s proposals. A factor to be taken into account is that many people are already in receipt of at least **some** state money. One of the Group's advisers suggests the additional expenditure might be £75 million a year. But, need I say it, whatever the cost it will be only a fraction of the amount we spend on defence.

It would be foolish to suggest that money by itself would solve all the problems of the disabled. There would of course remain a whole series of difficulties arising out of disability. Some are perhaps largely unavoidable – like the pain, discomfort and loneliness suffered by many. Others are definitely avoidable – the unsuitability of so much institutional provision, the inadequacy of the welfare services, the flights of steps to public lavatories and libraries. But the assurance of a decent income is still a fundamental need, and not simply because it will relieve the kind of poverty that ought not to exist in a country as rich as ours.

The fact that the disabled are so often poor, and that organisations concerned with them constantly have to appeal for funds, militates against good relations with “normal” people. It is extremely difficult to respect, treat as an equal, someone towards whose support one has just

given half a crown, or who cannot afford to pay his way in the pub or contribute his share of the family's weekly expenses. Like so many modern reform movements, the Disablement Income Group is founded on a belief that the weaker, less productive members of society should not be regarded as inferior beings and segregated off from the rest of their fellows. They should instead be given special help, in a way which safeguards their dignity and self-respect, to enable them to live as normally and fully as possible as an integral part of the community itself. The extent to which this ideal is realised must surely be the measure of a healthy and truly civilised society.

Justice, Not Charity²²⁸ (1969)

The Disablement Income Group (DIG) was started only four years ago, but it has since had an astonishing amount of coverage in the press and on radio and TV. No doubt some of this success is owed to the skill and determination of people like Mrs. Megan du Boisson, the co-founder and now Honorary Director, who is herself disabled by multiple sclerosis. But more basic is the strength of the case being put by DIG. This is set out clearly in their latest leaflet, **Towards a National Disability Income** (Paper No. 9, from DIG, Godalming, Surrey)²²⁹, which makes it distressingly obvious that many of the disabled in Britain live in varying degrees of poverty and deprivation. The provision of a National Disability Income would obviously do much to right this unjust and inhumane situation. But, unfortunately, it is evident that the present government has no intention of acting on DIG's main recommendations. Proof of this depressing fact, if proof was needed, came with the publication in January of the **White Paper on Social Security**²³⁰. The White Paper does make certain welcome gestures in more or less the right direction. A degree of wage-related long-term sickness benefit will in time be helpful to some people, as will the proposed allowance for all those 'wholly or largely dependent on help from other people in coping with the ordinary functions of daily living' – though one wonders what exactly this will mean in practice.

Neglected Groups

However, nothing has yet been done for many thousands of disabled housewives who receive no allowance at all at present, nor for the many low-paid workers who need a loss-of-earnings supplement such as the war and industrially disabled are already receiving whenever necessary. Two other major neglected groups are the 150,000 men and women who have never been able to work and thus have to exist on the ridiculously inadequate rates of Supplementary Benefit; and families with severely

disabled children who do not even receive an extra tax allowance. It is true that the White Paper hints at further measures in the summer, when the results of the government survey of the disabled will be known. But it is difficult to be hopeful that these will have more than a marginal effect on the scandalously low incomes of so many disabled people. Nor is there much chance of removing the disincentives to self-help and rehabilitation which are built into most of the present allowances in the form of harsh earnings rules.

Publication of the White Paper offered the perfect opportunity for initiating the radical changes advocated by DIG, and the government have shown a sad lack of imagination in letting it pass. The danger is that the few advances which they are proposing will obscure their complete failure to tackle the problem at the level required. The trouble is that basically they appear to be content with the present system. The Secretary of State for Health and Social Security, Richard Crossman²³¹, has even written to DIG saying he regards Supplementary Benefit, on which so many disabled people are reliant, as 'a fair and sensible means of helping a lot of people'. It is hard to imagine how the Minister can come to a conclusion like this in view of the evidence and arguments put forward by DIG. Clearly, dependence on Supplementary Benefit is inappropriate for those who have special long-term needs arising from permanent disablement. This is recognised by everyone where the war and industrially disabled are concerned. Why should the case of the 'civilian' disabled, whose needs are effectively the same, be considered so different?

Truly National

DIG contends that if National Insurance Scheme is to be truly national then it should offer adequate cover against disablement to everyone, including the groups who are at present left out altogether. So, housewives should be brought into the scheme on their husbands' contributions, for example, and people too disabled to work from childhood should receive a pension on their parents' contributions at the age of sixteen. In addition, the scheme should recognise clearly, with appropriate scales of benefit, the difference between permanent disablement with its extra long-term financial needs on the one hand, and temporary sickness, unemployment and retirement on the other hand.

Obviously, no matter how it is arranged, the first priority is to get more money quickly to seriously disadvantaged individuals and families. This would not only relieve much intolerable strain immediately, but would eventually have various desirable social effects – fewer children growing up in poverty, for instance. The mere fact of making the equation 'disability = poverty' occur less often would help to integrate the disabled and their families into society. Very low economic status is an unnecessary extra barrier to add to the unavoidable ones produced by disablement and dependency.

But even in the unlikely event of Supplementary Benefit rates being raised somehow to a specially high level for the disabled, and becoming payable to those in low-paid work, this would still not be the right means for tackling the problem. Because it is not just a question of having enough money. The way in which the money is made available is important too. DIG's proposal, that disability should be one of the things against which every member of the community is adequately covered within the National Insurance Scheme, could have a further series of valuable social consequences if implemented. It would help to make the fact of disablement, and its special needs, a reality to the whole population as something that can happen to us all, It would also help to create a climate in which people who are at any given time disabled are thought of **more as people like us** than as **them** – a quite separate category of people who are 'looked after by charities and the Assistance Board²³²'.

It may seem contradictory to advocate emphasising the special needs of the disabled as a means to their greater acceptance as equal members of society. But this is the kind of paradox that runs through all attempts at integrating stigmatised minority groups. My belief is that progress can best be made in this difficult task not by denying, but by acknowledging openly, the special disadvantages and differences created by disability, and by doing what can be done to compensate for these. The important thing is that the means chosen by the community for helping its handicapped members should involve the least possible devaluing 'charity' implications, and should affirm the common humanity and equal rights and dignity of everyone no matter how disabled or dependent. In my opinion DIG's proposals meet these criteria.

Community Care

There are two further questions raised by DIG's suggestions which are of particular relevance to residential Homes. Everyone pays homage to the official policy that 'community care' is preferable in general to 'institutional care' – in other words, that every effort should be made to enable handicapped people to live in their own homes for as long as possible. Yet in practice the present financial arrangements work in quite the opposite direction – as they do for other groups such as the elderly, the mentally handicapped or children in care. Numbers of people who struggle on at home receive little or nothing in the way of financial help. This means that severe financial strain may be added to all the other difficulties that can arise in a household when a member is disabled. Yet once the struggle is abandoned, that person will be maintained by the state in a hospital or Home at a cost of anything up to £50 week. There is also the related fact that local authority expenditure on home-help services is only about a third of what they spend on residential Homes. One does not, of course, want to see less money spent per resident in Homes. But it is evident that while the financial system is so weighted against anyone who tries to remain at home, the admirable policy of encouraging community rather than institutional care is unlikely to have the desired results.

Paternalism

My second point concerns the manner in which money is made available when someone does in fact become resident in a Home. At present, the bulk of the cost is usually paid by the State (in various complicated and often anomalous ways) directly to the authorities of the Home for 'looking after' the person concerned. It seems to me that bypassing residents like this is wrong. It encourages a paternalistic approach on the part of those running Homes, and a passive attitude in the residents. If DIG's proposals were implemented one ought instead to have a situation where someone who needs residential care would (with help where necessary) act on his own behalf in entering into an arrangement with a Home. He would be provided with the services he required in exchange for an agreed proportion of his pension. In a more or less subtle way his position within the Home might change from being that of a helpless dependant to being more that of a client or consumer.

It would be foolish to claim that such a re-routing of funds through the individual would eliminate the shortage of suitable Homes, or would do anything fundamental to improve the situation of those receiving residential care. But I believe it would be a move towards greater choice and increased self-respect for the severely handicapped. It might also provide a better basis for experimenting with various forms of resident participation in the management of Homes, besides making it more feasible for small groups of residents to get together to organise their own arrangements for care.

These are perhaps minor considerations compared with the central fact of widespread poverty amongst the disabled living at home. But they help to add weight to DIG's contention that merely tinkering with the present system simply will not do. This system is full of anomalies, and the help it gives is often inadequate and may be stigmatising. The alternative arrangements proposed by DIG would do much to prevent the disabled falling far behind the rest of the population in living standards as happens at the moment. They would also further assist the integration of disabled people into society by giving them the financial help they need in the way which best preserves their dignity and self-respect.

Megan Du Boisson – An Appreciation²³³ (1969)

The death of Megan Du Boisson in a car accident on May 10th was felt as a personal loss by many thousands of people. Megan was travelling to the fourth A.G.M. of the Disablement Income Group, of which she was co-Founder and Honorary Director. In its four years of existence D.I.G. has recruited over 10,000 members, and has mobilised an astonishing amount of pressure and influence aimed at achieving a better life for the disabled of this country. Megan Du Boisson was from the beginning the moving spirit, with charm and skill and driving determination creating and strengthening the Group until it became a power in the land.

I cannot imagine Megan as ever having been an ordinary woman, but she led a 'normal' life with her husband and children until she developed multiple sclerosis a few years ago. It was while trying to cope with this devastating personal crisis that she discovered to her horror that many disabled people were worse off than she. Apart from their physical or mental handicaps they were also living in varying degrees of poverty, while she and her husband happened to have an above-average income. So, with a friend, Mrs. Berit Moore, who also had multiple sclerosis, Megan started D.I.G. to press for reform of a financial system which adds so many burdens to those already faced by the disabled and their families.

Before her death Megan had the satisfaction of knowing that D.I.G. had helped to bring about the Government's proposed constant attendance allowance – the first financial recognition of severe permanent disablement for all those not disabled through their work or while in the forces²³⁴. No-one knew better than Megan, however, just how inadequate this proposal is and how much remains to be done. Perhaps her greatest achievement was to leave behind an organisation well-fitted to keep up the pressure until the radical changes needed are brought about.

D.I.G. has never been a one-woman band, but Megan's influence has shaped it thoroughly. It is almost miraculous to me that a movement

which is largely led by middle class people working on behalf of 'the poor', should yet have remained so responsive to the needs and wishes of its ordinary members. D.I.G. has a democratic constitution, of course, but that alone would not have been enough to prevent the feeling of 'them' and 'us' that one finds in most similar organisations. The key so far has been Megan's extraordinary ability to keep the confidence of thousands of people living in circumstances quite removed from her own. Coming from an impeccable middle-class background herself, she managed somehow never to condescend or to lose touch with the realities of other people's lives. She was Megan to everyone, not as a democratic gimmick but because she tried to treat people as equals whether or not they were powerful or useful or personally congenial.

Megan kept herself closely in touch with the growth-points of thinking about disability, and never withdrew from the awkward and complex pressures of constantly evolving situations and new insights. Throughout she was having to cope with the unpredictable physical and emotional stresses of her own degenerative disease, often forced to work from her bed but rarely missing an opportunity to further D.I.G.'s aims. She was sustained in all this by her family and many friends, and by her deeply held liberal convictions and principles.

Megan seized every chance to publicise D.I.G. – meeting reporters, arguing with Ministers on television, talking on the radio, serving on committees, and appearing on platforms. No doubt part of her enjoyed all this. Yet she also experienced the genuine self-doubt of a sensitive and basically humble person who occupies the limelight. Of her appearances on television and radio she once said to me that they made her feel she was prostituting herself. It was this kind of sensitivity, coupled with a determination that nonetheless the job must be done, which helped her avoid the jealousy and hostility she might otherwise have attracted. Her overriding loyalty to the members of D.I.G., and her constant awareness of merely being the spokesman for those who were living in poverty, enabled her to steer clear of the pitfalls of hob-knobbing with 'the great'. She never became arrogant, although her initial uncertainty on the subject of disability gave way to strong convictions and the ability to analyse problems and situations in considerable depth.

I did not know Megan well in her family and personal life. But she was a friendly, encouraging presence there in the background who always made time to read anything I published. She would write detailed comments in reply to the points I made in letters, never dismissing them

out of hand when she disagreed but paying me the compliment of arguing each one carefully and in detail. Above all she was someone who would ring me up from time to time and apply just the right sort of pressure to make me feel I wanted to do something for D.I.G.

The death of this remarkable woman is great loss for the disabled of this country – and for Britain as whole, too. We must hope that the excellent foundations she has laid will be built on by us all in the years ahead. Because the best possible memorial to Megan will be a democratic and militant D.I.G., which will not rest or compromise until all disabled people have adequate incomes as a right.

Disablement²³⁵ (1973)

'As a society Britain has what amounts to an elaborate system of discrimination against the disabled. We do not ensure that they have good housing, adequate community services, employment with dignity, or an adequate income'. Professor Peter Townsend came to this depressing conclusion in 1967 after reviewing the evidence of a survey carried out under his direction²³⁶. Similar conclusions have been reached by others who have studied the subject or who have conducted investigations in recent years. There may be arguments about some details of the situation, and about how it should best be tackled. But there is no disputing the fact that people who are physically (or mentally) handicapped in Britain today often do not get the help they ought to receive in a just and humane society.

Before attempting to show some of the major difficulties, particularly financial, besetting the disabled, the questions of definition and of incidence must be touched on. The blanket term 'the disabled' is often used to cover a great variety of conditions and degrees of handicap, both physical and mental. I shall have particularly in mind, however, young- or middle-aged people whose capacity to perform the ordinary functions of daily living has been seriously impaired, for example by accidents or by conditions such as rheumatoid arthritis, multiple sclerosis, cerebral palsy, the aftereffects of polio, heart disease or strokes. It is true that this loosely defined group constitutes a minority within a minority. Many of the disabled find that their condition is not serious enough to be more than a nuisance. Of those who are substantially impaired, a majority are elderly, or mentally handicapped, or suffer from complete or partial blindness or deafness, or conditions such as epilepsy and chronic bronchitis. While there is certainly no intention to imply that their situation, and particularly that of the mentally disabled and the elderly, is any less important or less in need of action, I have three main reasons for concentrating on the particular sub-group

described. Firstly, I am most familiar with their circumstances. Secondly, it is largely they who feature in the publicity currently given to the disabled. And thirdly, focusing primarily on one group in this way helps to illustrate more clearly in the space available some of the main issues involved in the whole complicated field of disablement.

Until a national survey was started for the Department of Health and Social Security in 1968, nobody had troubled to investigate the numbers of people with disabilities in this country. Part of the difficulty has been that there is no generally accepted definition of disability or handicap, and estimates of the numbers involved vary enormously according to which definition is adopted. It has been suggested, for instance, that at any one time in Britain there might be only about 85,000 people who use wheelchairs, and many of these may not be completely chair-bound²³⁷. Professor Townsend calculated that there were in 1967 very roughly a million and a half, or 3 per cent of the population, in groups officially described as physically or mentally disabled²³⁸. The Government survey, the first two volumes of which were published in May 1971²³⁹, estimated that there were about 3 million people in Britain (excluding children and those in institutions) with some physical, mental, or sensory impairment. Of these, one and a quarter million were defined as very severely, severely, or appreciably, handicapped²⁴⁰. Estimates and surveys in other countries have produced figures of 6 per cent or more having some degree of disability. In the United States references to 1 in 7 of the population, or about 27 million, having a permanent impairment are common, although the usefulness of such statistics may be doubted. The President's Commission on Chronic Illness which produced this figure itself pointed out that most of the people involved did not require specialized facilities or services.

The Government national survey of the disabled in Britain was undertaken partly as a result of the skilful and determined pressure brought to bear by the Disablement Income Group. DIG was started in 1965 by two housewives who were themselves newly disabled by multiple sclerosis, an unpredictable degenerative disease of the central nervous system which usually affects young adults, which has no known cause or cure, and which brings increasing paralysis in its later stages. Faced in middle life with such a devastating personal situation, Mrs Megan Du Boisson²⁴¹ and Mrs Berit Moore discovered that many people with disabilities were even worse off than themselves, since they both had husbands with above-average incomes. They found that a great

many people not only had to cope with the problems of disablement itself, but were also living in varying degrees of poverty and deprivation. They started DIG to try to remedy this situation.

Eight years later the Disablement Income Group is a nationwide organization, with forty local branches throughout the country. It has a membership of over 10,000, made up of both the disabled and of interested supporters. The Group has received a great deal of publicity through the press, radio, and television, and has the backing of most of the voluntary and professional bodies in the field. It can claim to have played a large part in bringing the needs of the disabled before the public and the Government, and in stimulating various expressions of concern for their problems. There have been several Private Members' Bills presented to Parliament, and the disabled have received frequent mention in debates. The Government has made certain extra social security provisions. And there have been rallies, lobbies, and resolutions at party conferences and many other national gatherings.

The sort of deprivation DIG has been revealing is startling in a society which prides itself on its Welfare State. It is true that in many respects Britain is one of the best countries in the world in which to be disabled, with its network of social security arrangements, the National Health Service, local authority health and social service departments, special education and training facilities, and the array of voluntary organizations. Nevertheless, there are huge gaps in both the social security system and the health and welfare services, and we are still a long way from having the kind of comprehensive provision which the disabled really need, and which a country as rich as ours can afford. This applies with particular force to the question of income maintenance.

The Disablement Income Group has highlighted the fact that from the financial point of view there are two distinct classes of people who are disabled—much as there are two nations in old age, according to Richard Titmuss. Those in the first group have at least a reasonably adequate income drawn from one or more sources. They may have acquired sufficient private resources through high earnings before disablement, through inheritance, or through marriage. They may have received compensation for an accident, or have been insured privately against becoming handicapped. They may in some cases be able to work and earn a good living despite disablement. Finally, and most importantly for purposes of comparison, there are people who have

become disabled while in the armed services, or as a result of their paid work, and who therefore receive reasonably scaled state pensions and allowances. A very severely handicapped man in these last two categories, married and with two dependent children, might in 1973 receive up to £40 a week – above the average industrial wage for men – made up of a basic pension, plus various allowances. Should he become able to return to work despite his handicap he would still retain his basic weekly pension – up to £ 11.20 at present rates. If his pension was less than this amount, and if his capacity to earn had been diminished by disablement, he would also be paid a loss-of-earnings supplement in compensation.

In contrast to this relatively well-off group are the hundreds of thousands of men and women who may suffer from equally severe or worse handicaps, but who are not fortunate enough to have any of these sources of income. There are several major categories in this neglected group. Firstly, the severely disabled person who has worked but whose disability arises other than as a result of his or her paid employment or while he was in the services (for example, as a result of multiple sclerosis, rheumatoid arthritis, or accidents at home), may be entitled only to Invalidity Benefit plus allowances for any dependents. Often this has to be made up by Supplementary Benefit, but at 1973 rates for a married man with two dependent children this means a total income of perhaps £15-£18 a week, plus an allowance for rent. This includes both the long-term addition of 50p a week payable after two years' receipt of benefit and family allowances. The Supplementary Benefits Commission is in addition able to make certain 'exceptional needs' payments to the long-term sick and disabled, both in the form of weekly allowances and of lump sums, but it is known that these extra payments in fact average out at less than 50p a week per person, and in November 1970 were given to only 20 per cent of the 170,000 sick or disabled persons who had been receiving Supplementary Benefit for two years or more²⁴². There can be no question of such 'special provision' being remotely adequate in the vast majority of cases.

An early letter from DIG's files, typical of many received through the years, illustrates something of what this situation can mean to a family. In 1967, after thirty years in work, the writer of the letter was unemployed and registered disabled. His income from Sickness Benefit and allowances amounted to £8 13s 6d a week, on which he had to keep himself, his wife, and their fourteen-year-old son. The rent alone came to

£2 4s 3d. He said: 'We do not have meat in our family now, we cannot afford it'. This family was not in fact even receiving the minimum laid down by the Supplementary Benefits Commission because, like many others, the husband was affected by the 'wage stop' (the regulation which stipulates that no one can receive more in benefits than the average amount per week he was earning when last in employment). The application of this rule to the long-term disabled has been modified, and the benefits payable to a man in similar circumstances are today higher in real terms. But these improvements have not eliminated the poverty of many individuals and families. 120,000 'Invalidity Pensioners' were still dependent on Supplementary Benefit in November 1970 according to the DHSS Annual Report for that year.

A second important category of neglect involves an estimated 200,000 severely handicapped married women under the age of 65 who are not eligible for any state benefits in respect of their disablement. Women who run their homes and bring up their children are not considered to be 'gainfully employed', and so are not insurable under State schemes. Unless the housewife also happens to be working outside the home when she becomes disabled, or has recently been in paid work for at least three years, she cannot claim Invalidity Benefit. If her husband is working, she is not even eligible for Supplementary Benefit, however low his income may be. For assessment purposes she is considered as an extension of her husband, and no one in full-time employment may receive help.

Another letter received by DIG illustrates this second large area of need, and also gives some idea of the kind of strain that lack of financial help can put on families with a disabled member. It is from a man whose wife has been practically helpless for five years following a stroke. He writes:

In order to pay my way I have to work at least six hours over time, which means I am away from home eleven hours a day. I have to get up just after 5.00 a.m. to prepare my wife's midday meal and our breakfast and to get her washed and dressed and leave the place tidy. I return home at 6.10 p.m. but only to start work again. Sometimes I feel I'd like to run out and leave it all behind, but the ties are too great. I hope I shall always feel this way.

Faced with this kind of situation some husbands give up work to look after their wives and children, and they all then exist on Supplementary Benefit. Some men, understandably, cannot face such a struggle, so their wives go into hospital (often one for the aged and dying) and the children have to be taken into care. Yet as DIG has pointed out so often, the cost of a hospital bed for the wife, plus the cost of keeping the children in care, would cover several times over what it needs to keep the family together, even if this included payment for nursing and domestic help at home. It is true that a proportion of families would still break up under the other strains that disablement brings. But if adequate help were available there would be at least a better chance of survival.

A third group hard-hit by the present lack of comprehensive provision is that of about 150,000 physically or mentally handicapped men and women who either have never been able to enter employment, or whose contribution record is insufficient to qualify them for insurance benefits. They therefore face a lifetime of subsistence on Supplementary Benefit, with no prospect of ever attaining a standard of living comparable with that of the majority in this country. Usually they are unmarried, and therefore do not enjoy the care and services that married people often receive from their partners and children. People in this category are entitled at 1973 rates to £7.40 a week Supplementary Benefit plus a rent allowance (which amounts to only 65 P a week if they are non-householders living with relatives or elsewhere).

Fourthly, at present no special allowances or tax concessions are made to many families which are bringing up a severely handicapped child at home. Fifthly, there are no allowances, except once again the most inadequate Supplementary Benefit additions, for the majority of elderly people who are disabled or sick but who are struggling to manage at home on the basic retirement pension. The constant attendance allowance introduced in November 1971 and extended in October 1972 helps only a minority of the needy in all the five categories described so far.

Lastly, there are the many low wage-earners who have some degree of physical or mental handicap. It is thought that they may account for a considerable proportion of the thousands of families which live at or below the subsistence level laid down by the Supplementary Benefits Commission. The present social security system for the 'civilian' disabled gives no special help to the person whose pay is low because of

disability, although the Conservative Government's ill-conceived Family Income Supplement Scheme may do this incidentally in a very small way.

It is also worth mentioning that many of the long-term unemployed receiving Supplementary Benefit are likely to be disabled in some degree, although not actually registered as such. In addition, amongst those who are officially registered with the Department of Employment and Productivity as disabled but capable of full-time work, the unemployment figure is 14 per cent (1972 figure). Even this does not show the true rate of unemployment amongst the disabled, because many who would be capable of some work are not included on the Department's register if they are considered unable to hold down a full-time job.

It is not possible to go into the question of employment in any detail here, but clearly it is relevant to the financial situation of the disabled. One of the strongest desires of most disabled people is to be able to do an ordinary job of work. Unfortunately, in a great many cases the opportunities for them to do so are limited by their handicaps, and also by deficiencies in facilities for rehabilitation, training, and retraining, by inadequate help from Disablement Resettlement Officers, and by prejudice amongst employers and employees. For the most severely disabled there is a lack of suitable home-work schemes. Where work of any kind is obtained, all too often it is menial and/or underpaid.

The sort of impact that the lack of any proper financial provision for disablement has in the community was shown in some detail by Professor Townsend's survey. He says:

Altogether 60 per cent of the households surveyed had a total income of less than £10 a week, and another 36 per cent less than £20. (A third of the households, it should be remembered, contained three or more persons.) Three quarters had less than £50 savings. Nearly half depended partly or wholly on National Assistance and about 5 per cent might have qualified for supplementary assistance had they applied for it. There is no doubt that a disproportionately large number of the disabled live in poverty or on its margins²⁴³.

Similarly, the 1967 Tower Hamlets Survey²⁴⁴ found that only 17 disabled people out of 201 interviewed had an income of more than £10 a week²⁴⁵.

Low as these income figures were by any standards in this country, they do not by themselves tell the whole story. It must be appreciated that disability usually involves various extra expenses for the individual and his or her family. There may be additional wear and tear on clothes and shoes, special equipment and accessories may be desirable, and extra heating is often necessary for those whose mobility is restricted. When the disabled person has to spend many hours alone a telephone can become an essential. Going out, whether to work or for social reasons, may be particularly expensive, because public transport is often difficult or impossible to use. For the man who would normally do much of his home maintenance himself, disability will probably mean employing workmen instead. The housewife may find her ability to run the home and bring up her children greatly reduced or lost altogether, and she therefore has to pay something for home-help. Most local authorities only supply this for free where income is around Supplementary Benefit level, and in any case the home-help service, like many others which local authorities provide, is usually quite inadequate to meet the demands placed on it. Again, for some people it is necessary to employ assistance with nursing or daily care, and here the local authority services are even more unlikely to be of use.

All these extra expenses caused by disablement may, of course, be a burden to those who are in work or whose relatives are maintaining them, as well as to those receiving social security. As we have seen, the extra State help given with such special expenses, even to those on Supplementary Benefit, is wholly inadequate, and in any case involves degrading forms of application. The same comments apply with equal force to most sources of financial help from voluntary societies.

The implications of the lack of adequate financial provision for many of the disabled, and the extra expenditure they may incur, can be seen clearly in the area of housing. Peter Townsend and Sally Sainsbury²⁴⁶ found that 20 per cent of their sample were living in houses which were deficient in three or more basic facilities, such as an indoor lavatory, a hot-water supply, or a bath. In Tower Hamlets²⁴⁷ 38 per cent of the sample had no inside lavatory, and 45 per cent no bath. Both surveys

showed that stairs were also a major difficulty. In the Townsend study 74 per cent had to use flights of stairs either inside or outside their accommodation, while 33 per cent had to negotiate stairs inside and outside. In Tower Hamlets almost 40 per cent had to use a flight of stairs to reach their homes, and in many cases more than one. A lot of the most inadequate housing in both surveys was privately rented, and the tenants had sometimes been on local authority waiting lists for many years. The Government national survey estimated that 15,000 severely handicapped people needed rehousing, and 75,000 required structural alterations to their accommodation: it confirmed that the lack of basic facilities occurs mainly in private rented accommodation. Only one-fifth of householders in Townsend's sample were buying their own houses, as compared with two-fifths of the general population. Apart from lack of the necessary income, mortgages are in any case difficult or impossible to come by for people who are not medically fit at the time of application.

Besides the basic deficiencies of a good proportion of the houses in which the disabled live, there are indications of many failures on the part of local authorities to carry out minor adaptations and provide aids which are clearly needed. Townsend quotes high figures for disabled occupants who could not open or shut windows, use the gas or electricity meter, turn taps, use a sink, or reach cupboards. Where special aids **had** been provided, they were usually simple ones which made life much easier. The beneficial psychological effect of retaining one's independence in daily living activities, and in entering and leaving one's home, scarcely needs pointing out, and its importance for long-term relationships within the family must be equally plain. Townsend calls for local authorities to give the disabled greater priority on housing lists. He also proposes special local authority work forces to execute a carefully planned blitz of adaptations on suitable dwellings when an occupant becomes disabled.

The slowly emerging picture of widespread poverty and hardship amongst the disabled, together with the pressure for reform brought to bear by the Disablement Income Group and other organizations and individuals, drew from the Wilson government many statements that they

were aware of and sympathetic to the problems of the long-term sick and disabled. As a sign of their concern, they helped Alfred Morris's Chronically Sick and Disabled Persons Bill to become law just before the 1970 general election. The main feature of this legislation was an attempt to compel local authorities to expand their social services for the disabled living at home, and there were various other miscellaneous provisions. It is to be hoped that the Act will in particular eventually prod local authorities into making more satisfactory provision for home care, but the Government has not pressed for its full implementation, and it has been easy for many councils to evade their apparent obligations – if only by imposing stringent means tests. The Act has never been quite the charter for the future of the disabled that has been claimed. And the danger is that, with so much publicity giving the impression that a great deal more is now being done, it may tend to obscure the central question of income maintenance.

The Labour Government also had several financial proposals for the disabled in the pipeline when the election was held. The chief one was for a new earnings-related sickness benefit to become payable, following the six months short-term sickness benefit, to men and women who were covered under the National Insurance Scheme when they became permanently disabled and had to stop work. The Disablement Income Group resisted the Labour Government's attempts to describe this 'premature retirement' pension as an invalidity pension, because it had no element of scaling for the degree of handicap and made no attempt to compensate for the extra expenses resulting from disablement. The scheme would have created new anomalies between those disabled early and late in life, and between those with more or less severe handicaps. It also did nothing for people who had never been able to work. In the event this proposal was lost when Labour failed to be re-elected.

Rather more satisfactory was the other main Labour Government proposal, which was improved on and enacted by the Conservatives as soon as they took office. From November 1971 a tax-free, non-means-tested, non-contributory constant attendance allowance has been paid to those who need frequent day and night care. Children, the elderly, and the mentally handicapped are included. Originally, an estimated 50,000 people were expected to benefit by £4.80 a week. But by March 1972,

75,000 awards had already been made. (This take-up rate is in marked contrast to the 50 per cent rate for the Conservative Government's means-tested Family Income Supplement, which extends a small supplementary benefit to the lowest paid workers with children.) In October 1972 the full attendance allowance was increased to £5.40, and a new reduced rate of £3.60 became payable to people needing either day or night attendance. Government estimates were that eventually about 250,000 would qualify at the reduced rate.

This constant attendance allowance undoubtedly represents a significant advance for the severely disabled of this country, establishing as it does several important new principles from which a more equitable system could grow. But three points must be made about the allowance. Firstly, many people in need will not qualify for it – those who struggle on and manage to look after themselves, for instance. Secondly, the comparable allowances for the war and industrially disabled can amount to as much as £13 a week. And thirdly, it must be evident that not even these allowances would cover the cost of frequent nursing help to keep a very severely handicapped person at home.

Apart from the attendance allowance, which applied only to the most heavily disabled, nothing was proposed by the 1964-70 Labour Government for the thousands of housewives who receive no help at all, or for virtually all the other groups which have been mentioned as needing comprehensive state cover in adversity. But what was most disturbing about Labour's policies was their revelation of a fundamental failure to consider the question at the level required. Basically, they appeared to be content with the system much as it was²⁴⁸. When Richard Crossman was Minister of Health and Social Security, he wrote to the Disablement Income Group saying that he regarded Supplementary Benefit, on which so many disabled people are reliant, as 'a fair and sensible means of helping a lot of people'. Yet from so many angles means-tested Supplementary Benefit is a most inappropriate form of assistance for 'the poor' and particularly for those who have special long-term needs arising from disablement. This is recognized where the war and industrially disabled are concerned, and there seems no reason why the 'civilian' disabled should be treated differently.

When the Conservatives were in opposition they made helpful noises about the need for a proper disability pension, and to their credit they were quick to implement and extend the new attendance allowance. But

judging from their Family Income Supplement scheme, they are in practice even more content than Labour with large-scale recourse to means-tested subsistence allowances. The general Tory approach to welfare benefits and services does not augur well for the disabled and other handicapped minorities, and it seems unlikely that the party of selectivity and the 'lame duck' philosophy will ever be able to tackle the question in the manner required. Their pensions Act, due to come into operation in 1975, makes no mention of disability²⁴⁹. The latest government proposal for a form of 'negative income tax' leaves out 10 per cent of the population, including it seems most of the non-employed disabled, and the Supplementary Benefits system will remain.

What the Conservative Government has actually done, in addition to legislating for the attendance allowance, is to introduce certain extra payments for people receiving Sickness Benefit after six months of incapacity. From September 1971 a small 'Invalidity Pension' of up to £1 a week (depending on the age at which incapacity starts) has been paid, plus extra children's allowances. Wives of invalidity pensioners are also allowed to earn up to £9.50 – instead of £3.10 – without loss of benefit.

This scheme is not so different from the Labour proposals, and it is open to the same basic objections. Although it may be seen as a move towards giving the National Insurance pensioner parity with the industrially disabled, it introduces new anomalies by leaving out both the disabled housewife and those handicapped so early in life that they have never been able to make sufficient contributions to qualify for benefit. Apparently, it is intended in 1975 to reduce the qualifying contribution period from a minimum of three years to that of one, but of course this will still exclude large numbers of people. There is no element of scaling for degree of disablement; and retention of the traditional 'all or nothing' approach means that invalidity pensioners themselves are still harshly discouraged from undertaking part-time work, although for some this would be both feasible and highly desirable. Incidentally, one of the ironies of this new-style increase was that about half the 400,000 beneficiaries lost some or all of their entitlement to Supplementary Benefit and ended up no better off.

It is understandable that for historical and other reasons the contributory principle is felt to be important. But an overriding principle of fairness demands that some means be found of bringing everyone within a truly comprehensive scheme. The Disablement Income Group

contends that if a national insurance scheme is to be truly national – like the National Health Service – it should offer adequate cover against disablement to everyone. So, housewives should be brought into the scheme either on their husband's contributions or on their own. People who have been too handicapped to work through disablement from childhood should be franked into the scheme at the age of sixteen, with special allowances being payable to their parents before this age. The basic pension should be paid even to those who can earn or who have private resources, but it should be taxable so that those in least need receive least benefit. People who are unable to work at all should receive the full pension, with a reduced rate being payable to those assessed as able to work despite substantial disablement. All the appreciably handicapped ought also to get a special tax-free allowance, solely to meet their unavoidable extra living expenses.

It is important that a comprehensive new scheme should recognize clearly, with appropriate rates of benefit, the difference between the category of short-term sickness, on the one hand, and that of permanent disablement with its special needs, on the other. At the moment, someone in bed for a week with flu may receive virtually the same insurance benefit as someone facing a lifetime of total paralysis, or dying slowly of cancer. It is obvious that Sickness Benefit and other allowances are scaled, even with earnings-related supplements, simply to tide people over limited periods off work, not for years of disablement. In the short term, most people can dig into savings or cut down on luxuries to get by. A longer period off work may mean a few debts or an overdraft at the bank, but these can be put right when things get back to normal. Permanent reliance on state benefits, perhaps with a growing family to cater for, and certainly with extra expenses arising out of the disablement, is a very different matter. It requires very different provision.

Clearly, no matter how it is arranged, the first priority is to get much more money quickly to many seriously disadvantaged individuals and families. This would not only relieve intolerable strain immediately, but would eventually have various desirable social consequences – fewer children growing up in poverty, for example, and some families being saved from breaking up. The mere fact that the equation 'disability equals poverty' would occur less often would in itself help the disabled to participate more in society. Very low economic status adds extra barriers to those associated with disablement and physical dependency in our society.

But even in the unlikely event of Supplementary Benefit rates being raised to an adequate level for the disabled, special disability allowances becoming payable to those in work, to disabled housewives, and to families with handicapped children, the situation would still not be satisfactory. It is not simply a question of having enough money. The way in which the money is made available is extremely important. If disability could become one of the eventualities against which every member of every family was adequately insured under the National Insurance Scheme, this would help to make the fact of disablement, and its special needs, a reality to the whole population as something that can happen to us all. It would also help to create a climate in which people who are at any given time disabled are thought of as 'people like us' rather than as 'them' – a quite separate and stigmatized category 'looked after by the Assistance Board and the charities'. To see the importance of this point it is necessary to abandon the usual vision of a large group of fit, normal people (us) regarding a small group of poor unfortunates (them). Instead, it has to be recognized that everyone is at least potentially a member of the second group, and that the standards thought right for the majority should govern the kind of provision to be made for the whole community without exception. Basing a campaign for a decent state pension for the disabled mainly on the premise that everyone ought to be adequately insured against the chance of becoming handicapped or having a handicapped child, should be more successful and more constructive socially than attempts to stimulate generosity for a pitied minority.

A comprehensive social security system must be the first priority on any scale of the needs of the disabled. But, as I have said, it would be wrong to give the impression that all their problems would be solved if adequate finance was by some miracle provided overnight. There are many other difficulties in the lives of the disabled – although in fact they are often closely related to the economic problem. There is the unsuitability of arrangements for the severely impaired, thousands of whom languish in large residential institutions. Tragically, Sir Keith Joseph was at the 1972 Conservative Party Conference boasting of his record in building many more such institutions than Labour, when what is urgently needed is

suitable ordinary housing with background care provided, as in the Fokus schemes in Sweden. I have already touched on the inadequacy or non-existence of many local authority services which may make institutionalization necessary in the first place: this situation is not going to be transformed just by the passing of the Alf Morris Act. I have also indicated that the need for employment with dignity is a particularly vital question where the disabled are concerned. Then there are the various anomalies in state help with personal transport, and the need to eliminate architectural barriers such as flights of steps to public libraries and lavatories.

Grave deficiencies exist in educational provision for handicapped children and young adults. Medical and social rehabilitation facilities for certain groups such as housewives, the elderly, the mentally handicapped, and the very severely disabled, come in for increasing criticism. Despite progress in recent years, much more could usefully be done in the field of sport and recreation, both by enabling the disabled to participate as far as they can and by ensuring that audience and spectator arrangements are suitable.

I would also suggest that, despite the excellent rescue work some of them undertake, a large proportion of the voluntary societies concerned with the disabled are ripe for reform, amalgamation or abolition. It seems to me that many of their problems stem from the poverty of the disabled and the consequent necessity for raising large sums from the public and other sources. Such legalized begging, with its often-degrading stimulation of feelings of pity and guilt, breeds a sense of superiority in the fund-raisers and donors, and produces subservience and a sense of stigma in the recipients. The constant emphasis on the need for money corrupts and trivializes relations between the disabled and the public. There is also unfairness in the present competition for a limited amount of charitable resources. Some causes have a natural appeal – cats and dogs and young children, for example – but the aged and mentally handicapped do not evoke the same kind of response, although their relative needs may be greater.

Perhaps in the long term the most important drawback of the present system is that the need to raise so much money helps to ensure that many voluntary societies do not tackle problems at their roots. The financial advantages of registered charity status are considerable, but the Charity Commissioners insist that no charity may campaign for

political change. The result is to help emasculate a number of organizations which ought to be active politically if they are to fulfil their aims properly.

Apart from the areas discussed above where reform is needed, there remain the personal difficulties which may accompany disablement, such as pain, fatigue, depression, loneliness, and frustration. Perhaps money cannot directly relieve problems like these, although the assignment of bigger Government funds for medical research would help in the long term, but it seems to me that the right kind of arrangements for income maintenance are as important as good medical services in providing an encouraging basis for the many positive developments which can also result from disablement. Even very severe disability need not turn out to be the fate worse than death that most people assume it to be. Many of the physically handicapped find that in time their physical and medical problems cease to be a constant preoccupation, and become more of a background nuisance. They turn their attention to the question of participation in ordinary life, refusing to think of themselves as totally 'sick', but rather as disabled in some respects and not in others. In education, work, and family and social life, attempts are made to break down the barriers and prejudices between themselves and the rest of society. This is not a matter of denying their need for special compensatory help, but of a feeling that such assistance ought not to diminish anyone's right to be treated as a full member of the community.

This implicit challenge to some of the prevailing values of society seems to me a healthier response to the personal experience of disability than the acceptance of a dependent and unequal position as a helpless invalid. But there are powerful social and psychological pressures on the disabled person to give in and adopt the largely passive role which is traditionally expected of him. For this reason alone, it is important that our social security system and social services should be designed to eliminate stigmatizing poverty and to encourage every impulse towards rehabilitation and participation in society.

Finally, the present situation of many of the physically disabled in this country cannot be considered without reference to that of other groups

which are handicapped in one way or another – by old age, by mental breakdown or impairment, by all the conditions covered in this book. It is, I believe, time for the Disablement Income Group to get together with bodies such as Shelter, Age Concern, and the Child Poverty Action Group, to try to work out a common strategy for change. The continued existence of seriously disadvantaged minorities in our relatively rich society poses far-reaching questions about that society's values and priorities, and particularly about whether the present distribution of resources is the best that can or ought to be achieved. The Labour Party in office effectively abandoned any idea of redistribution in favour of the poor, while the Conservatives have shown themselves to be set on redistribution in favour of the rich. It is evident, however, that the plight of the various under-privileged minorities will not be remedied except by a major shift of available resources in their favour and an associated transformation of our approach towards equality and social justice.

It is tempting to imagine that all the problems of poverty will sort themselves out if our standard of living continues to rise. But although the situation of the disabled and other similarly placed groups may be improving slowly in absolute terms, their relative share of the country's resources is if anything decreasing, and therefore they remain in poverty compared with the majority – and even more so compared with the affluent minority. This failure of the idea of automatic progress towards the elimination of poverty, on both a national and an international level, has become clear in recent years. It is equally clear that the pursuit of unlimited economic growth may be said to be leading to disaster. In searching for the principles and means by which the disabled may be helped to share fully in our national life, we are confronting one aspect of what is perhaps the central moral and political challenge of our time.

[I am grateful to Phyllis Willmott for her comments on an early version of this essay. She is not of course responsible for any remaining factual errors or for the opinions expressed. P.H.]

Policy Paper to the 1973 Conference of the Disablement Income Group

The holding of a Policy Conference represents an encouraging trend in DIG's affairs. We appear to be at an important turning point, and a fundamental review of policy is very much needed. DIG's CANDI²⁵⁰ proposals for an earnings-related disability pension have been rejected by the government, and they have come in for increasing criticism in recent months. There have also been strong feelings amongst some members that on issues like the Jimmy Martin affair²⁵¹, and the case of the thalidomide children's compensation²⁵², DIG has missed golden opportunities to exert pressure on behalf of all disabled people. It is noticeable that the word poverty had scarcely been used for the last 4 years until the publication of The Poverty Trap²⁵³²⁵⁴. And, to some longstanding members, it has seemed that the official DIG has become too ready to defend its record: too pleased with compliments from government Ministers which many pressure groups would regard as the kiss of death; and too easily led into thinking that having people in wheelchairs haunting the corridors of Parliament represents in itself a major achievement.

The recent controversy about the TV program "A Question of Confidence"²⁵⁵ highlights the fears some of us have about DIG's current role. In view of the lack of action by parliament, DIG members might reasonably expect the Group to become more militant as time goes on, and to ally itself with other groups which are demanding action, not words from politicians. But when an individual member did in fact strongly criticise parliament on "A Question of Confidence", official DIG was quick to repudiate what had been said. What was worse, DIG also helped to instigate a witch-hunt against the people who were for once trying to allow a small dose of unedited anger and urgency to surface on television.

It seems important to raise these issues in the context of a conference about the National Disability Income. It is not sufficient for us simply to look at various possible 'solutions' to the financial problems of disabled

people, choose the best scheme, and go forth to do battle once more. We shall not know which is the best scheme unless we have first become clearer about the basic principles by which all proposals should be judged. And, even if we do adopt the very finest scheme, it will be of little use if we do not ensure that our efforts are actually going to assist the process of achieving a better life for all disabled people. We need to look carefully at the history of achievements in social provision in this country, and in the light of this decide whether our present heavy emphasis on making friends with politicians is in the best interests of disabled people. This point is every bit as vital as the question of which pension scheme we adopt; because, if we do not also get our strategy and tactics right, we run the risk not only of wasting a great deal of effort, but also of seriously misleading all the disabled people who so desperately need a proper disability income.

Of the sections which follow, the first sets out a list of basic principles which might be adopted to guide future discussion of any proposals for a disability income. The reason for attempting to formulate some basic principles is that it is above all on the level of principle that every ordinary member of DIG can be involved in policy-making. Deciding about principles is emphatically not a job for the experts. Their job is firstly to help us to understand the issues; and secondly to translate in detailed schemes the principles which we have decided are the right ones.

The second section of this paper summarises and criticises DIG's proposals as set out in CANDI.

In the third section, Peter Townsend's suggested disability pension scheme is examined.

And lastly, some outline proposals are put forward for a National Disability Income based on the existing Industrial Disablement Scheme.

A National Disability Income

Suggested principles by which any proposal should be judged.

1. The main lines of any National Disability Income must be devised in close consultation with DIG ordinary disabled members, and with other groups which would be vitally affected (e.g., The Mental Patients Union²⁵⁶, the National Federation of Old Age Pensioners' Associations²⁵⁷ and the Claimants' Unions²⁵⁸).

2. The rate at which a N.D.I. for the physically impaired us paid should be graded according to the degree of impairment; and the rate payable should not be dependent on previous earnings, contribution record, sex, age, or anything else of this kind.
3. The N.D.I. should avoid creating disincentives to working, to rehabilitation, and to independence in daily living activities.
4. The N.D.I. should not be means-tested. And, at least at the 100% rate, it must lift all disabled people, including those disabled now, off reliance on means-tested Supplementary Benefits.
5. The N.D.I. should be financed out of progressive taxation on incomes and wealth, since abolition of poverty amongst the disabled can only be achieved by large-scale redistribution.
6. If a proper N.D.I is to be introduced in stages, then it must from the beginning concentrate help on those in greatest poverty, and the most severely impaired, regardless of age or working status.

DIG's earnings related pension

DIG's present policy as set out in CANDI advocates a disability pension scheme which is dependent on the earnings records and contributions of employees. This "premature retirement" pension was urged on the present government for inclusion in their earnings-related retirement pensions Bill²⁵⁹. It would be payable, at a rate related to previous earnings, to anyone who had to give up work before retirement; and for those who became disabled but could still do some work, a partial pension would be paid. Flat rate pensions would be given to disabled housewives, and to people unable to work from childhood. Children and the elderly would be excluded from the disability pension, but all appreciably disabled people might qualify for expenses allowances and extended constant attendance allowances.

As we know, the government refused to have anything at all to do with these DIG proposals. It is arguable that DIG should from the beginning have refused to have anything at all to do with the government's retirement pensions Bill. Such a Bill represents a bonanza for the insurance industry and the stock-exchange. But for all except a small proportion of the people who have to pay for the scheme it represents a massive con-trick. For the lower paid, and those who experience long periods off work – and this includes most women and many disabled

people – the Bill represents a con-trick twice over, since the future benefits they are likely to receive during retirement will be derisory and will do little or nothing to raise them off reliance on Supplementary Benefit. In addition, the Bill does nothing for the present retirement pensioner, and very little for anyone who retires in the next decade or two. Since so many pensioners become disabled at some stage, and so many of them are women, DIG should have had a direct interest in attacking the whole Bill for the immoral piece of work it is.

In any case, DIG's proposals for earnings-related disability pensions to be incorporated in the Bill were far from what is required. Some of the objections to CANDI have been summarised by Townsend in **The Guardian**²⁶⁰ and by Tony Lynne in **New Society**²⁶¹. But it is still important to look briefly at the consequences of the proposals set out in CANDI.

Under DIG's scheme, the degree of impairment or handicap is not taken into account. The pension is to be payable only in the event of complete inability, or reduced ability, to work during normal working years.

This means that whatever their relative degrees of impairment:

- (a) Both present and future generations of the elderly would receive no disability pension at all; and nor would children, or most of the present disabled under retirement age.
- (b) The non-insured "housewife", and other people who had paid few or no contributions, would receive only the flat rate of pension.
- (c) The lower-paid, those who experience much sickness and unemployment, who do part-time work, or who spend years looking after children, would qualify only for a low rate of pension if in years to come their ability to earn was lost or substantially reduced through disablement. Such disadvantaged groups would include most women, most of the so-called "mentally disabled" and "mentally handicapped", and many of the physically impaired who manage to work for part of their lives.
- (d) The top rates of disability pension in the DIG scheme would be paid only to people in the future who became disabled after 20 years or so of high earnings. Inevitably, most of the people in this favoured group would be men, and many of them would have held

professional and managerial jobs – with all the opportunities this usually gives for accumulating resources and taking out private insurance.

So, it appears that DIG's proposal would give no special disability pension to any of the elderly, nor to children, nor to many of the younger disabled alive today. It is difficult to square this with the DIG Constitution's stated first aim: "To secure the provision for all disabled people of a national disability income and an allowance for the extra expense of disablement". The absence of a pension for the elderly (so many of whom are women) is also extraordinary in view of the figures which CANDI itself gives from the government national survey of the disabled.

Of the very severely, severely, or appreciably impaired in Britain nearly twice as many are aged 65 and over as are below this age, and there are twice as many women as there are men. In gearing their pension scheme primarily to men, of working age, DIG is to say the least showing a strange sense of priorities.

Finally, it is worth quoting the terms in which DIG itself discussed the last Labour government's earnings-related sickness benefit proposals – which were similar to those made in CANDI. Writing editorially in Progress (Spring 1969), Megan Du Boisson strongly criticised the Labour government scheme as set out in its White Paper. She said:

"There is one phrase which must not be allowed to stand. This says that the long-term sickness benefit "will be in effect an invalidity pension". It will NOT be an invalidity pension, in effect or in fact, for it does not take into any account the cost of invalidity, and is paid at the same rate or an even more generous one to persons of a lesser degree of disability. What would constitute an invalidity pension would be assessment according to the degree of incapacity"

There is no reason why DIG's policy should not change with time. But before abandoning such basic principles, set out as recently as 1969, we need to be sure there are good reasons for doing so. CANDI does not make out a convincing case for the new principle of disability pensions

related to previous earnings. It is necessary therefore to look at alternative proposals.

The Townsend approach

Peter Townsend's disability pension proposals are based on an assessment of a person's degree of independence in performing certain daily living activities (such as dressing, shopping, climbing stairs). This is a very much better scheme than DIG's present earnings-related policy. It is particularly strong in including all existing and future disabled people of all ages, whether working or not, on the same terms. However, there are some features of the Townsend scheme which appear to raise serious problems.

1. It is very difficult to measure accurately an individual's performance in carrying out daily living functions. How, for example, can assessors know how much effort or pain is involved in disabled people's efforts to wash or dress themselves? It seems also that there would be continual dispute – particularly in the case of fluctuating or progressive disease – about how honest someone was being; about whether certain aids to independence were desirable; about whether a person or family should move to a more suitable dwelling to minimise any dependency; and so on
2. If the pension level is to be based on assessment of dependence in daily living activities, there will sometimes be a loss of income if a disabled person becomes more independent through the use of aids, adaptations, and rehabilitation services. In some circumstances, there could thus be strong financial pressures on the disabled person and their relatives not to strive to achieve maximum independence. This might be so, for example, where disabled people are only able to contribute to the family budget through their pension, or where the continued dependence of a disabled child was a useful source of extra finance to a low-income family.

3. Assessing the amount of pension by degree of dependence would be very unfair to severely impaired people who devote much of their energy to struggling to retain independence in their daily living activities. This unfairness is one of the criticisms which has to be made of the present Constant Attendance Allowances, welcome though they are as emergency measures. These tend to penalise someone with multiple sclerosis, for example, who just manages to live alone, as compared with someone with a similar impairment who lives with relatives, and not only receives regular assistance from them but an Attendance Allowance also. A further drawback of assessment by loss of independence would be the distressing need to apply for reassessment whenever someone with a deteriorating condition lost another function.
4. The job of assessing inability to perform daily living activities is one for which Occupational Therapists and Physiotherapists are best suited by reason of their training and orientation. But such people are in extremely short supply. So, it would presumably be left to doctors to carry out much of the assessment required. Doctors, however, are suited by their training and orientation to assess clinical impairment, not the effects this impairment may have in daily living.
5. The Townsend proposals are intended to include the so-called “mentally handicapped”, and the so-called “psychiatrically disabled”. But it is hard to see how a system of functional assessment, based on inability to carry our daily living activities, could possibly operate except to the disadvantage of many in these groups.

So, it appears that Peter Townsend’s disability pension scheme is streets ahead of DIG’s present earnings-related policy. But his proposals have their own serious drawbacks. It therefore seems necessary to look for another alternative.

The Industrial Disablement alternative

It is strange that public discussion of the disability incomes issue so often seems to skate quickly over the fact that we already have two state

pension schemes for the disabled operating in this country. War and Industrial Disablement pensioners are not often heard complaining about their pensions. Yet both schemes tend to get dismissed by commentators with a few sarcastic words about the fractions of an inch of amputated stump which the assessment panels are said to be obsessed with. There seems, however, every reason to look seriously at these schemes which have operated for many years with such apparent success. It may be that the Industrial Disablement scheme, in particular, can provide just the basis we need for the development of a “civilian” pension. The following outline proposals are an attempt to adapt the Industrial Disablement scheme to extend an adequate pension to all significantly physically impaired people in this country.

Outline scheme

The percentage of pension payable should be determined by the degree of physical impairment. This is a relatively precise method of assessment, with much less room for dispute than there is with schemes based on degree of dependence in daily living. It is also just the kind of clinical assessment which doctors are trained to carry out – diagnosis, prognosis, the measurement of amputations, limb movement, lung capacity, muscular power and control, brain damage, and so on. The Industrial and War Disablement schemes must already have much useful experience in this area which could help to ensure a quick start for a new scheme.

However, it should also be possible to associate the various kind and degrees of clinical impairments much more precisely than has been done in the past, with certain likely consequences of expenses and loss.

Studies would be needed to tell us what, on average, it means financially, in terms of loss of activity and independence, and perhaps in terms of pain and discomfort, for example to be completely blind or deaf, to have had multiple sclerosis for 10 years, to have chronic asthma or heart disease or severe rheumatoid arthritis, or to be born with cerebral palsy of various degrees of severity. The studies would be concerned merely with discovering what on average these conditions mean to groups of disabled people in terms of special difficulties and needs, so that percentage levels of pension could be set which were appropriate for certain types and levels of clinical impairment. Such studies would not however be concerned with actually assessing individuals for their

own particular pension, so the assessment problems associated with the Townsend scheme would not arise.

There are various possible ways in which the results of such research could be applied. Pensions could become payable within broad percentage bands up to 100%, with an individual's degree of clinical impairment determining the percentage payable. Periodic reassessment might be needed for fluctuating or progressive diseases and for children. But alternatively, with something like multiple sclerosis, for example, it should be possible to associate certain average levels of handicap and dependency with the number of years elapsing from the onset of the disease. This could mean, say, that after 4 years the person with multiple sclerosis would be entitled to a 40% pension, and after 10 years to a 100% pension, whether or not the disease had actually progressed to the extent which was on average expected. This might save the distressing need for regular individual reassessment to measure further deterioration.

The suggested scheme would include all present and future disabled people – children and old people, men and women, working or not working – all receiving a pension assessed on their degree of impairment alone. This would involve virtually no disincentive to rehabilitation, working, or attaining maximum independence in daily living. It is arguable whether or not the pension should be taxable so as to give reduced help to the better off. It is also arguable to what extent it would be possible and desirable at some stage to include in the pension an additional element to cover the sort of allowances which are in the Industrial Scheme paid separately – such as attendance allowance, exceptionally severe disablement allowance, and unemployability supplement. What cannot be questioned is that for people with the most severe levels of impairment and income of at least £30-£40 a week in present terms is needed. This is the kind of sum which it costs to incarcerate disabled people in institutions, but only a fraction of this amount is usually available to severely disabled people trying to live outside in the community.

Insofar as brain damage, or other measurable physical impairment is involved, the proposed scheme could include so-called “mentally handicapped” and “mentally disabled” people. But it seems unlikely that any scheme designed to fit the needs of the physically impaired will be really suitable for other groups, and it may be necessary to devise alternative arrangements for them if they are to receive comparable

benefits. The Mental Patients Union and other interested groups should be consulted on this point.

Clearly the above outline scheme would need to be discussed fully, and amplified and modified, before it could be adopted as DIG policy. There would inevitably be difficulties of implementation, and anomalies would no doubt arise. As with all schemes for measuring people and their performances, there are many points where the whole exercise seems quite mad. Nevertheless, the Industrial Disablement scheme appears to have worked reasonably well for nearly 30 years. It seems therefore to make sense for DIG to develop proposals along the same lines, to include all disabled people and to guarantee them financial help according to their degree of impairment

Section 6: Writings in and on the Union of the Physically Impaired Against Segregation (UPIAS)

Most people who've written about Hunt in passing believe his claim to have founded the Disabled People's Movement in Britain boils down to one letter to **The Guardian** newspaper in September 1972, asking other disabled people to join a 'consumer group' interested in different kinds of social care. While the group that emerged, the Union of the Physically Impaired Against Segregation (UPIAS), was ground-breaking and helped change how disabled people think about disability, that letter was a bit of a flop. As Tony Baldwinson has pointed out, most early members joined after seeing a different call-out in magazines specifically for disabled people (**The Cheshire Smile, The Magic Carpet, The Voice of the Disabled** etc)²⁶². Even in 1972, after all the public scrutiny of their income and living conditions, disabled people were still more easily reached by disability charities' magazines and newsletters than by the mainstream press.

It was unusual to see someone suggest that disabled people needed their own organisation to put forward their own views, but it wasn't unheard of. The Disabled Drivers Association had been around for over a decade, and (as Hunt points out in his **Guardian** letter) people who were labelled 'mentally handicapped' and 'mentally ill' were already getting together to criticise the services they used. It made sense for physically impaired people to get in on the act.

What was unique about UPIAS was who ended up joining and how they decided the group should to work. Nearly everyone who responded to Hunt's letter had either lived in an institution and was angry about how it was run, or lived in fear of being

moved into one if their fragile support arrangements broke down. A lot of early members had been involved in struggles within the Cheshire Foundation and Spastics Society, but they were joined by disabled people with other experiences – of Young Disabled Units in hospitals, rehabilitation centres, and of the discrimination and mistreatment that disabled people faced in society at large.

Many of those members also had experience of being part of social movements beyond the disability field. Ken Davis, for example, was active in the Campaign for Nuclear Disarmament, and other members had worked with feminist organisations. Most important in this respect was Vic Finkelstein, a South African political refugee. Finkelstein had been involved in the struggle against Apartheid – the laws which segregated black people in South Africa – and had been imprisoned and tortured for helping a Communist Party leader flee from the police. These members brought revolutionary new ideas to the question of disability. Feminism's insistence that the personal is political – that our private lives are influenced by inequalities in the world around us – was applied to disablement; showing that the dependency and powerlessness many disabled people experienced was not accidental and could not be separated from how this society worked. This point was developed through insights from Marxism – a philosophy Hunt had been interested in for a few years. Following Marx and Engels, Finkelstein and other members argued, the attitudes people in society have towards oppressed groups are based on how the society is set up; particularly who has power within it and how the economy works. To try, like DIG and the Cheshire Foundation had, to change people's ideas about disability by appealing to the better nature of those in power was to get things backwards. First, disabled people needed to actually do things on their own terms and take back some of the power that had been taken from them. Social attitudes would only change for good if they were successful.

Two things became clear early on: this new organisation needed to work out its ideas and figure out how to apply them,

and its members needed privacy to do that. Disabled people weren't often taken seriously by society, and to get anything changed members would need to be clear on what they wanted and well organised. Just as serious, for many members, was the risk of being 'outed' as a potential trouble-maker if you lived in an institution. The new group decided to take its time discussing its members' ideas and priorities, and to do this through a confidential circular – a sort of internal magazine that any member could write for, but only members were allowed to read.

This private conversation had some astonishing results. By looking seriously at each other's experiences of inequality and of trying to challenge it, members in London and the Midlands began to argue that the situation disabled people found themselves in was entirely a social problem, with very little to do with their bodies being different from the norm. Paying attention to how disabled people were excluded (to one degree or another) from all elements of social life – work, education, housing, political life, etc – they came to the view that disabled people were an oppressed group in society in much the same way as black and LGBT+ people and women. They also began to work out why this oppression was taking place; the social world had been built around workplaces that produced for profit, as disabled people found it harder to adapt to increasingly fast and intense forms of work, they were left out of decisions about how this world would look.

They also started to realise who benefited from their oppression. Using another argument from Marxism, Finkelstein and Hunt in particular argued that disability showed up a contradiction in modern societies. On the one hand, through advances in technology and practical know-how, it was now more possible than ever for disabled people to play a full role in social life. There were people in society who knew how to design accessible buildings, to make sophisticated mobility aids, and to organise personal support that made institutions unnecessary. There were personal computers that opened doors and dialled telephone numbers, and there were adapted

cars which people with limited mobility could drive. The segregated workshops had showed that workplaces themselves could be adapted so disabled people could do many manual jobs, and there was no good reason why they couldn't do professional or office jobs as well as anyone else. On the other hand, there was the disabling way society was organised which prevented these technologies being used. These included bosses who wouldn't pay for adaptations, local councils who wouldn't change the layout of their public space, buildings, or transport, and those that ran segregated institutions – who UPIAS saw as jealously guarding their own jobs, social status, and influence by blocking forms of support that would give disabled people greater freedom.

This put UPIAS on a collision course with those who ran residential institutions, special schools, and segregated services – i.e., services like day centres and 'disabled only' transport which kept disabled people separate from the social world rather than supporting them to take part in it. The progressive charities like the Cheshire Foundation and the Spastics Society were seen as particularly dangerous. They, according to UPIAS, segregated and oppressed disabled people in much the same way as the special schools and long stay hospitals did, shutting them away from society and imposing living conditions that nobody else would put up with. They couched this oppression, however, in the language of empowering disabled people to live freely, and of providing something like a home of their own. They had, to UPIAS members' minds, effectively tried to trick people who were concerned with disabled people's freedom to believe that something was already being done to bring disabled people into society, when in reality they were being shut away. While these segregated services continued to be built, UPIAS argued, there was little hope of resources being given to more empowering forms of housing and support.

The incomes campaign of DIG didn't fare much better in UPIAS's judgement. If disabled people were really oppressed in society, then it didn't make sense to slice up their oppression into single issues. A better income for disabled people was

desirable, and UPIAS had its own idea of what this should look like, but the price DIG was willing to pay for even small increases in some disabled people's income was far too high. By refusing to let disabled members organise around anything else under its banner, DIG had effectively tied its members' hands. Without action on education, work, leisure, and personal support, a better income wouldn't so much increase disabled people's freedom as it would compensate them for being unfree. It wasn't just that DIG's demands for a disability income were weak and wouldn't help most disabled people, or that it had become toothless by refusing to take on unsympathetic politicians (although UPIAS members believed both things); it was that it was undemocratic and could not respond to its members' real concerns.

These critiques would be worked out in a series of letters between UPIAS and figures from the Cheshire Foundation and Peter Townsend from the Disability Alliance – a breakaway from DIG which argued that a more aggressive approach was needed on the incomes campaign – and later in a meeting with the Disability Alliance which would be written up as a pamphlet; the **Fundamental Principles of Disability** (published in 1976). It was in these discussions, as well as UPIAS's **Aims and Policy Statement** (1975), that the Union put forward its own definition of what disability is. Where its opponents argued that having something wrong or different about your body meant that you would inevitably have less of a role in society, UPIAS argued that they were making a basic mistake. There may or may not be all kinds of negative effects of having an impairment – one might be easily tired, in pain, or likely to die young because of a bodily difference – but none of these explained why disabled people were shut out from a society that had proved it **could** adapt to include them if it wanted to. It was this lack of social adaptation – in living arrangements, at school, in work, on the bus – that really took people's abilities away; not the fact that they had missing or defective limbs, were blind or deaf, or had any other bodily or mental difference from the norm. There was then a very

important distinction between an impairment and a disability. An impairment is a fact about a person and how their body or mind works; it might involve pain or inconvenience, but it's part of life and one must put up with it. A disability, on the other hand, is a fact about society; the removal of someone's opportunities and freedoms because society has been built in a way so as not to include them.

The mainstream disability charities and campaign groups were fairly positive towards UPIAS when it started, but the relationship soon soured. Those working in institutions often responded by petty personal attacks – especially against Hunt. As one member living in a residential hostel run by the Spastics Society reported in 1975 in the Circular, employees were telling any disabled person who would listen that UPIAS was nothing but Paul Hunt's vanity project, solely driven by his 'hatred of all authority'. It did not and could not, according to Christopher Foxley-Norris (the Chairman of the Cheshire Foundation), speak for all Cheshire Home residents, let alone all disabled people – who he claimed were either perfectly happy with the type of care available in a Cheshire Home or unable to manage with any other kind. Even those in the wider disability movement most sympathetic to UPIAS, like National Federation of the Blind Chairman Fred Reid, had grave misgivings about its ideas and demands. Reid conceded that UPIAS was 'the authentic voice' of physically impaired people, but its strong demands for an end to segregated institutions and its gloves-off dealings with the other charities made it 'sectarian' – a group unwilling to work with others for the greater good²⁶³.

Both claims – that Hunt controlled UPIAS by himself and that the group refused to work with anyone else – are untrue. While Hunt was excited about the ideas coming out of UPIAS and did his best to push them forward with new arguments, the most radical claims that shaped UPIAS's arguments and positions came from other members. Both the idea that disability was essentially a social problem, and that it was a type of social oppression or a kind of mistreatment imposed on a group of people, were first proposed by Vic and Liz Finkelstein. While

Hunt took a key role in the discussions which developed this view, he was far from the only member working to make those ideas sharper. Similarly, UPIAS was happy to work with disability groups that didn't share all its ideas on practical projects that would improve disabled people's lives, **as long as** these projects included the people effected from the very beginning. UPIAS worked solidly for a few years with a traditional disability charity in Ealing, West London, to try and get the local council to talk to disabled residents about their housing needs rather than build new segregated hostels. Likewise, when Cheshire Foundation Trustee Hampton Inskip asked for their help to organise residents' committees in some Homes, UPIAS gladly agreed – although other parts of the Foundation quickly stopped the plan going any further. What UPIAS wasn't prepared to do was go over disabled people's heads by getting involved in campaigns that shut them out from making the major decisions.

The two most important roles Hunt played in UPIAS before his death in 1979 were as an organiser and a theorist who tried to turn the group's arguments and ideas into a way of understanding the world and acting on it. Firstly, using the experience he and other residents had gained in Le Court, Hunt made sure that all members were kept informed of what the Union and other disability groups were doing, that everyone contributed their skills and ideas to UPIAS, and that there were clear ways for the group to make decisions. There were all kinds of challenges getting a group of disabled people from all around the country started – especially as members could not afford high membership fees and had decided that they would not take money out of charity in case it cost their independence. Not only were there issues of how people were going to keep in touch, of arranging meetings and making them accessible, and managing all the group's letters and literature; but there were also real risks to members in institutions that the Union needed to deal with. Hunt was the main point of contact for members being victimised by institutional staff; he found out what members in institutions

needed, and marshalled UPIAS members outside to provide what help they could.

As a theorist, Hunt drew together his own and other people's ideas and turned them into an analysis of the world. While other people had come up with the idea that disability was a form of social oppression, it was Hunt who applied it to explain the situation disabled people found themselves in – why they were in poverty, why institutions existed, why they continued to be segregated even when it was clearly no longer necessary. Much as Hunt himself had during the '60s, many UPIAS members looked at decisions made by doctors and other medical professionals on one hand, and by local and national government on the other, as the immediate reason they faced disadvantage. After all, it was their medical needs that were used to explain why disabled people had to be kept apart, and it was government who called the shots on what housing, services, and income they would be provided. Hunt recognised these insights, but argued that the picture was more complicated. If disability was a kind of exclusion that was caused by how society was organised, there is never just one type of person or organisation with an interest in keeping disabled people down. Anyone interested in keeping society as it is – whether professionals, businessmen, charities or whoever else – could potentially either directly play an oppressive role or, more likely, give a job and social status to people who could manage the disabled population for them. This understanding helped Hunt pull together a policy document for UPIAS from a range of personal experiences of, and ideas about, different kinds of oppression, and allowed him to push these ideas further. This analysis didn't only explain why disabled people had ended up where they were – why decisions had been made to segregate and oppress them – but could be used to interrogate why new breeds of professionals interested in disability (academics, social workers, rehabilitation workers) acted in the way they did, and ultimately whose side they were on.

Despite how exciting the debate was, and how useful many members found these ideas when they organised with local disabled people, UPIAS wasn't always an easy organisation to be in. While the debates in the Circulars were pretty tame compared to those between other feminist, Marxist, or anti-racist activists at the time; members didn't go out of their way to be polite to each other when arguing a point. The general attitude was that disabled people had had muddled thinking pushed on them for far too long, and couldn't afford to be confused about anything now they were setting out on their own. If somebody put forward a bad argument about what the Union should do, it was more important to point out why their ideas were wrong than to worry about offending them – although the most fiery arguments were usually between close friends and political allies, and newer members tended to get a more generous hearing. Even so, this was the first time that many disabled people had been in a real hammer-and-tongs debate, and a number of people were either put off joining or only stayed in the Union briefly.

There were also problems with having a group of people, with very different types of experience and skills, spread all over the country in a time where transport and meeting venues were largely inaccessible. UPIAS members were involved in lots of local work – leading campaigns or, like Ken Davis and Maggie Hines in the East Midlands, organising disabled people-controlled alternatives to segregated services. Because UPIAS was a national organisation, however, it often appeared to members that it didn't play an active role in these struggles, and some began asking what it was actually for. For Hunt, Finkelstein, and a few other members, it was obvious that what UPIAS could do in the '70s was develop the research and thinking that these local campaigns needed to win and empower the disabled people they worked with. This, however, required members to commit to doing a lot of intellectual work – research, writing, and debating big ideas or the increasingly complicated way society dealt with disabled people. For some members, already working flat-out in campaigns where they

lived, there simply wasn't the energy or the confidence to do this work.

The writings in this section capture both the hope and the frustrations that were rolled of the first few years of UPIAS's life, and give an insight into how the arguments around what it meant to say that disability was both social and a form of oppression developed. As part of this discussion, Hunt was forced to go back and rethink several topics he had tried to deal with earlier in his life – from the nature of the Cheshire Foundation and the role of self-help groups to the place of academic research in a liberation movement. The conclusions he comes to, in conversation with his UPIAS comrades' critiques of disablement, constitute what I believe we can call his mature work; a body of arguments and analysis which came through re-evaluating everything he thought about disability. Hunt did not believe that he had reached all the answers – there were, as the reader will see, plenty of questions about social oppression and physically impaired people the Hunt knew he could not respond to fully. It is, however, the most nuanced and rigorous period in his thinking; applying the principles UPIAS had developed together to the complex power-relationships disabled people found themselves in, and to take apart the society which excluded them.

Letter to the Editor of the Guardian: 20th September 1972²⁶⁴

Sir,

Ann Shearer's²⁶⁵ account of the CMH conference²⁶⁶ **of** and not **on** the so-called mentally handicapped challenges our patronising assumptions about such people. It also has important implications for anyone who genuinely wants to help other disadvantaged groups. For instance, practically every sentence in her article could apply with equal force to the severely physically handicapped, many of whom also find themselves in isolated and unsuitable institutions, where their views are ignored and they are subject to authoritarian and often cruel regimes.

I am proposing the formation of a consumer group to put forward nationally the views of actual or potential residents of these successors to the workhouse. We hope in particular to formulate and publicise plans for alternative kinds of care. I should be grateful to hear from anyone who is interested to join or support this project.

Yours faithfully,

Paul Hunt

Priorities of Change
Letter to the Editor of The Cheshire Smile²⁶⁷
(1972)

During 17 years of living in various institutions for the disabled, and in the years since I left, certain questions have nagged insistently at me. What can be done to improve residential homes, centres, and hospital units for the physically handicapped? What alternative forms of care might be devised which would prove more satisfactory? What changes in society are required if severe disability is either to be eradicated or to become no bar to full social participation?

In discussion recently, a friend suggested that what was urgently needed was to have the views of people who are themselves in institutional care. Their ideas on the situation are more important than anyone else's, but are often the least taken account of by administrators, planners, and politicians. If disabled people living in institutions were able to work together to work out proposals for change, they could obtain national publicity and a say whenever their future was being discussed.

I should be very glad to hear from people who are interested in this proposal, and have it in mind to put them in touch with each other. Hopefully, this would lead to the formation of a group, the recruitment of more members, and eventually the holding of national conference on policies, priorities, and methods of achieving change.

Paul Hunt

Introduction to UPIAS Circular 3²⁶⁸ (1973)

As we agreed, this circular comes to you in confidence as a member (that is, it is not for general circulation, and articles and letters should never be quoted outside the Union without the explicit permission of the authors). It contains some letters from members (signed when the person's permission has been given), and 3 articles written specifically by members as contributions to our discussions. But first I want to put you all in the picture with regard to developments so far, and make a few suggestions about how we should continue our discussions.

There are at the time of writing twenty of us who regard ourselves as physically impaired, and have joined the Union by paying 25p (plus donations in some cases) and agreeing to take part in postal discussion. One non-disabled person sent 25p which I have returned. And a disabled person sent £10 for 'Life Membership' but did not comment on the Circulars and said she was unable to contribute to discussions at present. After some correspondence she has accepted her cheque back on the understanding that she is welcome to get in touch again when she can join on the same basis as the rest of us.

I am continuing to try to make contact with more people (and still have about 50 copies of each of the previous circulars available). I have also circularised most of the 'disability' magazines and some national papers and magazines with a short notice based on the last Circular.

Offers of help with our Union have been received from several organisations. The Central Council for the Disabled duplicated the first two Circulars for us. (Now that we have gone confidential [Member A] as a member is typing and duplicating this.). Peter Moss of the Campaign for the Mentally Handicapped wrote on seeing my **Guardian** letter, and on a subsequent visit he repeated their offer of help. (Friendly contact has also been made with the Union of Mental Patients which, like us, has just started and which has as part of its aims a Charter of Rights and

the eventual abolition of mental hospitals). Miss Morgan, Senior Social Worker at the Spastics Society, wrote to offer the use of their Family Assessment Centre for meetings or a small residential conference. Requests for information about our doings have been received from the British Council for Rehabilitation of the Disabled, the Disabled Living Foundation, and the National Association of Voluntary Hostels

One of the people who wrote after my **Guardian** letter has just been in touch again. She has connections with a London Housing Association that lets houses to various organisations which make themselves responsible for housing disadvantaged groups. She wanted to know if we would like her to formally propose providing a house for disabled people who want to live outside an institution. I explained that as a Union we were not in a position to take on such a responsibility, at this stage anyway. If members would be interested to take the idea any further perhaps they'll get in touch with me shortly. Otherwise, I shall encourage the woman to pursue her idea with an established voluntary organisation or social services department.

This brief survey brings us up to date with the main events so far. What happens from now on is up to us all, and I shall not be taking any more of the kind of autocratic decisions which seemed necessary to get something going. I had until recently, however, thought I should continue acting as some sort of Secretary and co-ordinator to the Union for the time being. But it has been pointed out to me that there is no reason why I should necessarily assume this role – and there are in fact very good reasons why I should not. If the Union is to thrive it is essential that it should quickly cease to be just 'Paul Hunt's group'. So, I want to put to you a few proposals which are intended to open the Union up to full participation by everyone.

At this stage of our existence there seem to be several practical matters which have to be seen to. (1) Someone has to hold our money, pay it out, and report to us on the state of finances. (2) Someone has to receive members' contributions to the Circular, say how many copies are to be printed, and arrange for them to be duplicated and sent off to members. (3) Someone has to be responsible for admitting new members, and for implementing any decisions we may make – for example, about members who do not respond with contributions to the discussion.

At the moment, Tonette Edwards is Acting Treasurer. (She reports that we have £11 in a special account with the National Westminster Bank at Petersfield). Tony has been Treasurer of the Residents' Association at the Le Court Cheshire Home for several years, and is used keeping books accurately. I suggest (a) that we ask her to continue as Treasurer for the time being. I suggest (b) that we adopt [Member B]'s proposal in her letter that various members should take it in turns to act as 'publisher' of the Circular. I should like to pass on the job to the first volunteer who contacts me. And (c) I suggest that another member should be asked to take on the job of membership secretary. Again, I hope to pass this job on to someone else very shortly. None of this means that I am opting out at all. In fact, it will leave me freer to contribute to the Circular – but the main thing is to ensure that I am divested of the kind of control I have had up to now.

Please let me have your answers to these proposals, together with comments and articles for Circular No.4. Hopefully I shall be able to pass the contributions on to the member who has taken on the responsibility for publishing the Circular for the time being.

Notes on the Nature of our Organisation²⁶⁹ (1973)

For my contribution to the present discussion, I want to take up some points from Vic Finkelstein's article²⁷⁰, because it seems to me to take the issues furthest. Having waded through it half a dozen times, I find the arguments in favour of calling ourselves Union of the Physically Impaired Against Segregation²⁷¹ very convincing indeed, and I support them fully. The second section contains much of value too. But I am not so happy with the way in which Vic argues that doctors know best about our physical impairment, OT's and physios know best about our physical handicap, and we know best about our physical disability. The distinction between the three 'levels' may be useful. But, in my experience, very often doctors and other medical people don't know what's best for us even at the level of prescribing drugs, ordering wheelchairs, deciding on operations, or giving exercises.

For one thing, there is no guarantee that a doctor or nurse or physio will necessarily be trying to do the best they can for us, nor is there any guarantee that they will be up-to-date or efficient. And there is in any case always still an element of doubt about what is the 'right' course. The element of doubt may be small with something like a burst appendix. But for practically every medical problem to do with physical impairment, the question of what is right for us is not in the least a neutral, technical, 'scientific' matter. On the contrary, it involves a range of judgements about risks, possible side-effects, chances of success or failures, expenditure of resources, personal and social consequences, and so on.

It is true that we expect doctors and other medical people to take the necessary actions to save our lives or prevent disablement if we are very ill, or unconscious. But we must insist that if they really mean well by us, then as soon as we are able to participate they will seek to involve us in any decisions which affect our lives. What in fact we experience all too often is that people like doctors and physios show quite unnecessarily

authoritarian behaviour in applying their experience and skills to physical impairment and handicap. This is wrong, not just because there is so much room for doubt about what treatment may be best, but also because in pronouncing on us as experts from on high, doctors and others are treating us like objects not people.

For these reasons I can raise no enthusiasm for the idea of our Union supporting the struggles of physios and OTs for an “equal and independent status compared with medicine”²⁷², unless at the same time they are explicitly struggling for ‘the patient’ to be placed at the centre of the decision-making processes involved in treatment and rehabilitation. Otherwise, we shall simply be exchanging one form of domination for another – and if I’m going to be oppressed then I’m not very interested in which particular profession it is that does the oppressing.

It is no good OTs being given the power to order us wheelchairs on their own initiative, if they simply go ahead and order what they consider the best model for our needs. What we must insist is that they order the model which they have helped us to choose as being the most suitable for our purposes.

So, in my view, we must not concede that doctor, nurse, OT or physio necessarily know best even about physical impairment and handicap. The importance of this point becomes clearest within residential institutions. Control is usually exercised primarily by doctors and nurses, with lay Management Committees invariably deferring to the pronouncements of the “Medical Officer” or “Matron”. The Committee assume firstly that medically trained people do always know what is best for the physical well-being of residents, and go on to suppose that it is therefore justified to impose certain rules and treatments for their own good (actual examples range from early bedtimes and refusal to allow electric wheelchairs or invalid cars, to not being allowed out in the rain, enforced bed-rest for minor ailments, and compulsory doses of Vitamin C to (supposedly) ward off colds).

I believe we need to oppose this kind of oppression as strongly as possible. We can of course oppose it on the grounds that even if a medical view is right, it should be no more imposed on disabled people than it is, say, on doctors themselves. But it is also vital to insist that medical opinion, even within the areas of impairment and handicap, is never totally objective or infallible. What we need is not ‘doctor’s orders’,

but doctor's advice both about the various possibilities open to us, and about the likely results of any course we choose.

Reply to [Member D]²⁷³ (1973)

[Member D]'s²⁷⁴ comments in Circulars 1 and 2 bring out some important points which I should like to take up as my contribution this time.

Firstly [Member D] advocates having spokesmen/salesmen to “sell” our Union to the public on the grounds that “anything that will help the Union stick in people’s minds helps”. Yet a few sentences later he is worried that we might become too “radical” – which he sees in terms of sitting “in the streets, waving placards, chanting”. He doesn’t think we are going to “convince the general public that to be disabled doesn’t mean mental backwardness if we exhibit ourselves in an undignified manner”.

There appears to be a contradiction here. On the one hand anything goes, according to [him], if it helps to get the Union into the public’s mind. But on the other hand, street demonstrations are wrong as they’re too undignified and “radical”. Probably [Member D] doesn’t really mean that all publicity is good publicity. I hope not, because there are many publicity gimmicks which would be disastrous for our Union. Any publicity we do seek must surely be carefully thought out, and closely related to our basic principles and aims. (Though personally I can’t see what’s wrong with street demonstrations if we decide they’ll serve a useful purpose).

But the thing that disturbs me most about [Member D]’s comments is that he sees our task as essentially that of convincing the “general public” we’re not mentally retarded²⁷⁵. I hope we’re setting out to achieve a great deal more than this, and won’t fall into the old trap of trying to prove ourselves “intelligent” and therefore more worthy than so-called mentally handicapped or mentally disabled people. I hope also that we shan’t fall into the other old trap of being obsessed with our “image”, of how we look to the “general public” (which section?)

As individual disabled people, we are all under tremendous pressure to worry about our personal appearance and the distress it may cause others. We are supposed to be exceptionally dignified and moderate in our behaviour by way of compensation, so that we put able-bodied people more at their ease and help them to be able to accept us as “normal”. For many of us, it is hard to get away from this “conforming” role, and instead to develop the confidence to treat other people’s awkward reactions to physical impairment as essentially their problem, not ours. A big help in developing this kind of personal confidence would be membership of a Union which is not obsessed with its collective appearance in the eyes of the public, but which is instead mainly interested in achieving fundamental change through unity amongst disabled people themselves, in solidarity with other oppressed groups. This will mean breaking with the policies and practice of other organisations for disabled people. However noisy and active such groups may be to start with, their leaders inevitably belong to or are drawn into the Establishment. They then come to value a respectable, dignified image at the expense of the real needs of the majority of disabled people.

Thirdly, I think it strange that in one sentence of his letter [Member D] says he doesn’t see the point of a Charter of Rights for disabled people, because he only wants “the same as the able-bodied want”. Yet in the previous sentence he has just explained that getting to a meeting requires either someone to push him in his wheelchair from his car, or else a building where there are no big steps or slights of stairs. Able-bodied people don’t usually require this kind of special help with access to buildings. So surely [his] access problem illustrates the fact that our rights as disabled people do need extra emphasis and action if we’re to be able to exercise them.

Fourthly, I disagree very strongly with [Member D] when he says “why bother” to work with other oppressed groups because he doesn’t feel particularly oppressed. It seems to me that [his] feelings about his personal situation are not the right way of deciding whether physically impaired people as a group in our society are oppressed or not. [He] may not feel oppressed (despite these steps that exclude him, and those people at the office who can’t bring themselves to address him directly²⁷⁶) – but then perhaps there were children in the coal mines in the last century who didn’t feel particularly oppressed. To know with complete certainty that disabled people are oppressed, we have to look not inward

at our personal feelings, but outward at the facts of our situation as a group in this society.

We must look, for example, at the 15% (plus) unemployment rate amongst disabled people. We must look at the low rates of pay for those who are working, and at their lack of promotion opportunities. We must look at the widespread poverty, bad housing, social isolation, segregation into special schools, clubs, Homes, and Centres, at the lack of entry into further and higher education... All these are objective facts, not feelings. We know also as a fact that this society has the wealth and the technical means to bring physically impaired people into the mainstream of life. It is precisely the glaring contrast between this real possibility of integration, and the present grim reality of what actually happens to so many of us, which is the basis for saying we are oppressed and must unite to bring about change in society. And since as a small, oppressed, minority group, physically impaired people are not in a position to bring about radical change on our own, we need to work with other oppressed groups which also have an interest in changing things.

Lastly, I disagree just as strongly with [Member D] on the question of the Union's attitude to the residential institutions issue. Discussing the draft Aims in Circular 1 he says – "Is it that you have been in an institution yourself that you feel strongly enough about it to make it a separate issue? I think it should be left out as I don't think it applies to the vast majority of disabled people in Britain today"

The short answer is yes, my previous experience of institutions does make me feel strongly about this issue, and did influence the draft Aims. It may be that the particular way institutions are singled out in Circular 1 can be improved on. This to me is largely a matter of presentation. I agree with [Member D] also to the extent that he points out that most physically impaired people will probably these days manage to avoid being put in an institution. But, at the same time, I do not agree for one moment with his assertion that the institutions issue doesn't "apply" to the vast majority of disabled people.

In the course of our discussions through the Circulars it has become clearer that a Union solely or even mainly for disabled people who live in institutions is unlikely to get very far on its own. Nobody can solve the problems of people in institutions for them, and their participation in the struggle is essential. But left by themselves, as a group they tend to be

weak and isolated, and their attempts to change the conditions that grind them down are doomed to failure. It is only by forging unity amongst themselves and establishing links with their natural allies – physically impaired people who live outside, and the other stronger groups which are uniting to overcome their oppression – that people in institutions can make real advances.

Does this mean that the vast majority of disabled people who already live outside institutions simply have to be kind to this unfortunate minority, and include them in “our” Union out of pity? This is what [Member D] seems to imply when he refers to some disabled people being “underprivileged”. (Is it privilege to be allowed to live amongst one’s fellow human beings, and to join them at school, work, and leisure?).

The basic impulse which makes some of us who live outside institutions concerned about the existence of such places and the low quality of life they provide, seems to me to be healthy. But the ever-present danger is that this impulse will turn into patronising do-gooding. This certainly will happen unless we are clear that involvement with the struggles taking place in institutions is essential for those of us outside for our own sakes too. If we ignore the reality of the many thousands of disabled people in segregated institutions, we shall be like middle-class negroes²⁷⁷ in America ignoring the existence of the ghettos when deciding whether or not black people in the U.S. are oppressed. Without involvement in the situation of the people who are at the bottom of our particular pile, we shall easily become confused (as [Member D] is) about the basic objective fact that disabled people as a group are oppressed.

When our personal situations as disabled people are relatively good, the remaining problems we ourselves face may appear to be on the way to solution. Those people at the office, or in shops or restaurants, who don’t know how to speak to us at first, or refuse us access to normal events, can often be persuaded to behave more acceptably in time. They can usually learn to tolerate disabled people who fight their way into areas of ordinary life. Particularly since the last War, the “general public’s” attitude has been modified gradually to accept the reality of some severely impaired people’s increased ability to take part in everyday life as advances in science and technology, and the changing requirements of the economy, have drawn more of us into productive work and other social activities.

Those of us who are currently experiencing the main benefits of these advances, and are being allowed to step our way up the ladder of social acceptability, can easily come to focus our attention on these personal gains and convince ourselves we're not oppressed. We then start to think the remaining problems of disability can be solved by a little more enlightenment all round, and a few more Alf Morris Acts of Parliament²⁷⁸. What we fail to see is that we are being drawn into a society which does not really recognise our right (or that of most people) to exist and flourish as equal human beings, but which instead ranks us in a hierarchy basically according to the amount of profit we can produce.

As disabled people, our comparatively low "profit potential", and our weakness in bargaining power, means that as a group – along with women, middle-aged and elderly people, those who've had mental breakdowns, etc – we are the first to lose our jobs and be cast on the segregated scrapheap whenever it suits the "needs" of the economy. If we're lucky we may be drawn in again, to do the worst paid jobs, when business starts to boom once more.

While we personally seem to be doing all right for ourselves, it is all too easy to forget that this is the reality of our situation as disabled people in society. But within segregated institutions – the ultimate human scrapheaps of this society – there is much less room for doubt about the need for a radical transformation before all disabled people can lead a decent life. The cruelty, humiliation, and physical and mental deprivation suffered by disabled people in institutions lays bare the essential nature of this society's relations with its physically impaired members. So those of us who live outside need involvement in institutions for our own sakes, so that we learn to fully understand our own situation and the nature of the forces which weigh us all down.

Cover Letter to 2nd Draft: UPIAS Policy Statemen and Constitution²⁷⁹ (1974)

Dear Member,

The enclosed draft **Policy Statement** and **Constitution** was originally written by me, and has been amended as a result of discussion within the Interim Committee. We have reached agreement on the general lines of the draft, but as you will see, there are some critical comments at the end.

The **Policy** draft is rather longer than originally intended, but it seemed necessary to include some description of the situation of disabled people if the proposals were to make sense. We could no doubt produce one or more short, popular versions or summaries for handing out at meetings and sending to enquirers, etc.

We've tried to take account of the views expressed in the Circulars, and feel we've learned a tremendous amount from them. But as you'll see, we've obviously rejected some of the arguments put forward, and it's difficult to see how this can be avoided since often the views conflict.

The idea we've tried to base the whole thing on is of the Union as offering help to disabled people in their struggles. We have the right to our own view of things, and the right to decide who we want to help and in what direction – that is, towards integration but not towards segregation. If this is clear, then we fully accept the point some members have made that we should not tell disabled people what to do. But arguing for integration is both our right as disabled people ourselves, and something which many disabled people clearly want too. If we concentrate on trying to set our policy based on the actual reality of the conditions of life we all face we may be unpopular for a while and remain very small, but to the extent that we are in fact based on the truth of disabled people's lives they will eventually respond to what we say.

The **Constitution** draft is intentionally as short and informal as we can make it. It's obviously riddled with holes for the legally minded to drive coaches and horses through. But it seems better at this early stage when we are so small not to have a formal, legalistic Constitution. We suggest that a thorough re-writing will be necessary in a year or so's time when we have found out the areas of difficulty.

The main idea has been to encourage a degree of real participation by members which seems lacking in most, if not all, other organisations for disabled people. At the same time, it seems to us necessary to allow a certain freedom for Executive Committee members to act decisively when necessary. It's a difficult balance to get right, but in our view, absolutely vital. Some of the clauses are based on the draft Constitutions of the Spinal Injuries Association²⁸⁰ and the Brittle Bones Society²⁸¹.

We suggest that you send in any general comments on these draft to me as soon as possible, and in any case before the 31st of August 1974. We will print them in the next Circular, together with our reply. Then we suggest that detailed amendments and other resolutions for the Conference should be sent in so that everyone can see them well before the Conference itself.

Yours sincerely
Paul Hunt – Co-ordinator

UPIAS Draft Policy Document and Constitution²⁸² (1974)

AIMS

1. The Union aims to have all segregated facilities for physically impaired people replaced by arrangements for us to participate fully in society.
2. We seek for all physically impaired people the necessary financial, medical, technical, educational, and other necessary help from the State to enable us to gain the maximum possible independence in daily living activities, to achieve mobility, to undertake productive work, and to live where and how we choose with full control over our lives.

POLICY STATEMENT

3. Disability and Segregation.

Britain in the 1970s has the necessary knowledge and the advanced technology to bring physically impaired people into the mainstream of life and enable us to contribute fully to society. But instead of the country's resources being concentrated on basic human problems such as ours, they are frequently wasted on projects like Concorde²⁸³ and Centre Point²⁸⁴, and on making sophisticated weapons of destruction. So, despite the creation today of such an enormous capacity, which could help overcome disability, the way this capacity is misdirected means that many physically impaired people are still unnecessarily barred from full participation in society. We find ourselves isolated and excluded by such things as flights of steps, inadequate public and personal transport, unsuitable housing, rigid work routines in factories and offices, and a lack of up-to-date aids and equipment.

4. There are a few individual examples of severely impaired people being able to overcome many of these barriers by the use of sufficient

resources in' the right way. They prove that integration is possible. But as a group we are still often forced to put up with segregated and inferior facilities. We get sent to special schools, colleges, or training centres. We are dumped in segregated factories, centres, Homes, hostels, and clubs. When we do manage to become mobile, it is often in antiquated tricycles or specially labelled transport. All these segregated forms of help represented progress in years past. But since the means for integration now undoubtedly exists, our confinement to segregated facilities is increasingly oppressive and dehumanising.

5. Recent advances.

The struggles of disabled people and their relatives and friends, together with advances in technology and medical science, have, it is true, resulted in larger numbers of us participating more fully in ordinary society in recent years. Some of the barriers which segregate us have been partially overcome or dismantled. So, a good proportion of people with paraplegia, or those who are blind, for example, have become able to work and to lead relatively active lives which would have been hard to imagine less than 50 years ago. These developments have meant a positive shift in the attitudes of some able-bodied people as they have responded to our presence amongst them.

6. Such advances show that general attitudes can be changed for the better. They also point to our increased participation in society as the principal means for achieving further change. But they cannot blind us to what remains the basic reality of the position of disabled people as a group. This society is based on the necessity for people to compete in the labour market in order to earn a living. To the employer of labour, the physically impaired are not usually as good a buy as the non-impaired. We therefore end up at or near the bottom of this society as an oppressed group.

7. Low bargaining-power.

When we do succeed in getting employment, our comparatively low productivity means that we have low bargaining-power when it comes to negotiating decent treatment and facilities. Physically impaired people are discriminated against in many ways. Our position is similar to that of many people who are middle-aged or elderly, who have had breakdowns, or are 'mentally handicapped', black, ex-prisoners,

unskilled workers etc. We are usually among the first to lose our jobs and be cast on the scrapheap when it suits the 'needs' of the economy. If we're lucky we may be drawn in again, to do the worst paid work, when business starts to boom once more. If we're unlucky, then we face a lifetime on the degrading, means-tested poverty line. If we're very unlucky we may be consigned to a life-destroying institution.

8. Institutions - the ultimate human scrapheaps.

The Union of the Physically Impaired believes that the reality of our position as an oppressed group can be seen most clearly in segregated residential institutions, the ultimate human scrapheaps of this society. Thousands of people, whose only crime is being physically impaired, are sentenced to these prisons for life - which may these days be a long one. For the vast majority there is no alternative, no appeal, no remission of sentence for good behaviour, no escape except the escape from life itself.

9. The cruelty, petty humiliation, and physical and mental deprivation suffered in residential institutions, where isolation and segregation have been carried to extremes, lays bare the essentially oppressive relations of this society with its physically impaired members. As in most similar places, such as special schools, there are some staff and volunteers doing their best to help the residents. But their efforts are systematically overwhelmed by the basic function of segregated institutions, which is to look after batches of disabled people and in the process convince them that they cannot realistically expect to earn a good living and participate fully in society. This function was generally appropriate when special residential institutions first came into being, since in the competitive conditions of the time many physically impaired people could not even survive without their help. But now that it has become increasingly possible for severely impaired people not just to survive, but also to work and become fully integrated, the need for segregated institutions no longer exists in the way it did. They have become seriously out of step with the changed social and technological conditions of Britain today.

10. Support for residents' struggles.

The Union of the Physically Impaired regards the neglected issue of institutions as of crucial importance in the field of disability. We therefore place great emphasis on supporting the struggles of residents in existing residential institutions for better conditions, for full control over their personal affairs, and for a democratic say in the management of their Home, Centre, or Unit. The Union strongly opposes all attempts by the authorities to impose restrictions on visiting; to fix times for getting into and out of bed; to limit residents' freedom to come in and go out when they wish; to enforce medical and nursing opinions, or to transfer residents to other institutions against their will.

11. The Union sees a need for a Charter which will focus on basic rights often denied when people are dependent on others for personal needs. Disabled people living in institutions will be offered help if they wish to organise locally in defence of their rights. The Union will develop an advice and mutual-help service to assist with negotiations, formation of residents' committees, etc. When asked, we will mobilise support and publicity on a national basis for those involved in particular struggles.

12. Alternatives needed.

The Union is opposed to the building of any further segregated institutions by the State or by voluntary organisations. We believe that providing adequate services to people in their own homes is a much better use of resources. We also call urgently for the provision of non-institutional alternative housing, such as the Fokus scheme in Sweden, which makes genuine progress towards secure, integrated, and active living for disabled people who need extensive personal help. The Union will try to assist anyone who seeks to move out - or stay out - of an institution. But we fully respect the feelings of individuals who regard institutional life as their best solution at the present time

13. Real choice.

The Union's eventual object is to achieve a situation where, as physically impaired people, we all have the means to choose where and how we wish to live. This will involve the phasing out of segregated institutions maintained by the State or charities. While any of these

institutions are maintained at huge cost, it is inconceivable that we will all receive in addition the full resources needed to provide us with a genuine opportunity to live as we choose. This point applies not just to residential Homes, hospital units, hostels, villages, and settlements, but also to other kinds of segregated facilities. As long as there are vastly expensive special schools, colleges and day-centres, heavily subsidised workshops and factories, and separate holiday camps and hotels, there can be no question of sufficient alternative provision being made to ensure that we all have real opportunity of equal participation in normal educational, work and leisure activities.

14. Disablement outside institutions.

Our Union maintains that the present existence of segregated institutions and facilities is of direct relevance even for less severely impaired people who may expect to avoid having to use them. Those of us who live outside institutions can fully understand the meaning of disability in this society only when we take account of what happens to the people who come at the bottom of our particular pile. Their existence and their struggles are an essential part of the reality of disability, and to ignore them is like assessing the condition of elderly people in this society without considering the existence of geriatric wards.

15. It is also true that the kind of prejudiced attitudes we all experience - other people being asked if we take sugar in our tea is the usual example - are related to the continued unnecessary existence of sheltered institutions. Those who patronise us are indicating that they think we are not capable of participating fully and making our own decisions. They are harking back to the time when disabled people had to be sheltered much more, and they imply that, really, we ought to be back in our rightful place – that is, a special school, club, hospital unit, Home or workshop. Physically impaired people will never be fully accepted in ordinary society while segregated institutions continue to exist, if only because their unnecessary survival today reinforces out of date attitudes and prejudices.

16. Medical tradition.

Both inside and outside institutions, the traditional way of dealing with disabled people has been for doctors and other professionals to decide what is best for us. It is of course a fact that we sometimes require skilled medical help to treat our physical impairments – operations, drugs, and nursing care. We may also need therapists to help restore or maintain physical function, and to advise us on aids to independence and mobility. But the imposition of medical authority, and of a medical definition of our problems of living in society, have to be resisted strongly. First and foremost, we are people, not ‘patients’, ‘cases’, ‘spastics’, ‘the deaf’, ‘the blind’, ‘wheelchairs’ or ‘the sick’. Our Union rejects entirely any idea of medical or other experts having the right to tell us how we should live, or withhold information from us, or take decisions behind our backs.

17. We reject also the whole idea of ‘experts’ and professionals holding forth on how we should accept our disabilities, or giving learned lectures about the ‘psychology’ of disablement. We already know what it feels like to be poor, isolated, segregated, done good to, stared at, and talked down to – far better than any able-bodied expert. We as a Union are not interested in descriptions of how awful it is to be disabled. What we are interested in are ways of changing our conditions of life, and thus overcoming the disabilities which are imposed on top of our physical impairments by the way this society is organised to exclude us. In our view, it is only the actual impairment which we must accept; the additional and totally unnecessary problems caused by the way we are treated are essentially to be overcome and not accepted. We look forward to the day when the army of ‘experts’ on our social and psychological problems can find more productive work.

18. The right kind of help.

We know that as a small, weak, minority group, disabled people cannot achieve a fully human life by their own efforts alone. We need and welcome the help of sympathetic able-bodied people. But the basic problem we face is our exclusion from full social participation. It follows that this oppressive situation can be put right only by disabled people actually taking a more active part in society. The efforts of professionals and other able-bodied people are therefore really constructive only when

they build on and encourage the self-help and activity of disabled people themselves. This is why our energies as a Union will be directed mainly towards discussion and common action with other disabled people. Neither we as a Union, nor able-bodied people, can solve other disabled peoples' problems for them. Those problems will be correctly tackled precisely to the extent that we all, as disabled people, become involved and active in our own rehabilitation.

19. The need for a Union.

Disabled people everywhere are already struggling against their isolation, segregation, and other forms of oppression. Every day each of us has to face our own individual problems. And we are now increasingly getting together in groups to tackle more effectively the problems we find we have in common. This is shown by the vast growth of disability organisations in the last 25 years in Britain. Our Union takes this process of coming together a stage further. We are not restricted to one aspect of physical disability (e.g., mobility or incomes), nor to people with one medical diagnosis, nor to those in one locality. The Union exists simply to offer help to all physically impaired people in the fight to change the conditions of life which oppress us and to realise our full human potential.

20. Action.

Various kinds of action in support of disabled people's struggles will be undertaken by the Union. Apart from publishing pamphlets and an open Newsletter, we will mount action campaigns on various issues. We will build up information and advice services, and organise financial, secretarial, and other forms of practical assistance. For example, individuals may ask for help in fighting bureaucratic delays and inefficiency, or a refusal to provide equipment, aids, or other kinds of service. Other people may want assistance in tackling organisations about the provision of ramps or lifts in buildings. Residents in institutions may seek help and national publicity if they are victimised by the authorities. People in sheltered workshops or centres may ask our support in their struggles to improve their appalling rates of pay. The Union will succeed only when it helps to achieve real benefits and improved conditions for disabled people.

21. Guidelines for action.

But our actions will become more effective if we make sure that we also learn from the practical struggles which take place. So, an essential part of the Union's task is to develop increasingly clear guidelines for further action. We will do this by careful discussion about what we and other disabled people are doing, and about the real nature of the problems we face at a particular time. We need to learn from our failures and successes, and so develop arguments and a theory which have been proved to work - because they do actually bring about practical gains for disabled people. In this way the value of our practical experience will be multiplied many times over, as the essential lessons learned from it are made available to other disabled people now and in the future.

22. Terms of membership.

Full membership of the Union is open to residents of Britain who are significantly physically impaired and who accept the Policies and Constitution, Full members are expected to take some active part in Union affairs, since the Union is firmly based on the conviction that, as disabled people, we can only make real progress through actively struggling for change. Members will of course have different capacities at different times, and 'active' here means at least some involvement in discussion of policy. Disabled people who feel they cannot at present contribute in this way may keep in touch by subscribing to our open Newsletter.

23. Able-bodied people who agree with the Union Policies and Constitution can become Associate members. Associate members may receive the open Newsletter and other publications, and may take part in meetings, discussions, and other events from time to time. But they are not entitled to vote on Union affairs, nor may they hold any Union office. Genuine supporters will recognise the need for us to control our own Union and so develop our powers of decision, organisation, and action. They will understand too, that since we experience daily the actual reality of disability, we are less likely than able-bodied people to be deceived about the true nature of our oppression and the radical changes necessary to overcome it.

24. Other oppressed groups.

The particular forms which oppression takes in this society differ somewhat for each distinct oppressed group. Some, such as people who are called 'mentally handicapped', or those labelled 'mentally ill', clearly have a great deal in common with us. Full membership of our Union is however based simply on the fact of physical impairment. This is because we believe the important thing, at the moment, is to clarify the facts of our situation and the problems associated with physical impairment. But it is fundamental to our approach that we will seek to work with other oppressed groups and support their struggles to achieve a decent life. What all oppressed people share is a vital interest in changing society to overcome oppression, and the Union is therefore anxious to join in common action to achieve such change.

25. Democratic control.

Democratic control of the Union rests with all full members, and policy is decided on a majority basis after thorough discussion in a confidential Circular or at General Meetings. Full discussion of policy by members is necessary if we are continually to develop our action and thinking along the right lines. But once decisions have been made, members undertake not to oppose them publicly while they wish to remain in the Union. Both elements in this combination are regarded as essential for genuine progress - thorough internal discussion by members, together with a refusal to indulge in public criticism of Union policies.

26. Day-to-day decisions on Union affairs are in the hands of an Executive Committee, elected by, and responsible to, all full members. The Executive Committee holds the Union funds. It arranges for the production of the internal Circular, the regular open Newsletter, and of occasional pamphlets and other publications. The Committee also speaks and acts officially for the Union on the basis of agreed policy. The overall task of the Committee within the Union is to facilitate the active participation and development of all members.

27. Special-interest groups.

Special-interest groups within the Union will be formed by members concerned with a particular aspect of disability. Examples may include

residents' rights in institutions, incomes, employment, special education, provision of aids and equipment, housing alternatives in Britain and overseas, medical and technical research, rehabilitation. Within the general principles of the Union, these groups will work out actions and ideas based on their special interests and experiences. Reports by them on particular topics will be published in the name of the Union from time to time.

28. Finance.

All registered charities receive valuable tax concessions, but they are not allowed to campaign directly for political change. We regard political involvement as essential if disabled people are ever to make real advances. So, in order to protect our independence of action we are not registered with the Charity Commissioners. Nor do we intend to appeal for funds publicly in the name of the Union. We believe the time has come for an organisation in the disability field which does not depend heavily on public fund-raising. We shall be free to speak and act on the basis of Union members' views rather than those of financial supporters and noble patrons. Union expenses will be met by subscriptions, by donations, and by such means as the sale of literature.

29. Other disability organisations.

The Union aims to ensure that all the organisations concerned with disability become fully democratic and responsive to the real needs and wishes of disabled people. We therefore seek a much greater say in all the organisations which affect our lives, both by Union members as individuals and by other disabled people. Any official Union representatives appointed to Committees of other groups will promote Union policies and report back regularly to members. In addition, the Union will keep a watchful, independent eye on the policies and practice of all disability organisations. We will try not to duplicate effort, and will welcome constructive comment and help from other groups. We will ourselves offer support and co-operation whenever possible. But the Union will not hesitate to speak out freely, and act independently, when we believe the interests of disabled people require it. It will be for disabled people as a whole to judge whether or not we are correct.

Constitution

1. Name.

The name of the Union is the Union of the Physically Impaired Against Segregation.

2. Aims and Objects.

The Union aims to have all segregated facilities for physically impaired people replaced by arrangements for us to participate fully in society. The Union seeks for all physically impaired people the necessary financial, medical, technical, educational, and other necessary help from the State to enable us to gain the maximum possible independence in daily living activities, to achieve mobility, to undertake productive work, and to live where and how we choose with full control over our lives.

3. Membership.

(a) Full membership is open to residents of Britain who are aged 18 or over, who are significantly physically impaired, and who accept the Policies and Constitution of the Union.

(b) Junior membership of the Union is open to residents of Britain who are aged less than 18, who are significantly physically impaired, and who accept the Policies and Constitution of the Union. (Note. This separate category is included only because there may be legal requirements to limit full membership to people who are over 18).

(c) Overseas membership is open to people normally resident overseas who are significantly physically impaired, and who accept the Policies and Constitution of the Union.

(d) Associate membership is open to people who are not significantly physically impaired, but who accept the Policies and Constitution of the Union.

(e) Junior and Overseas members have all rights in the Union except the right to vote or to hold Union office.

(f) Associate members may take part in meetings, discussions, any other events at the invitation of the Union, and may receive the Newsletter and other publications. They do not however have the right to vote, to hold Union office, or to take part in policy discussions through the internal Circular or at General Meetings.

(g) The subscription for all types of membership will be determined by the Union from time to time, and membership of each kind will lapse unless the appropriate subscription is paid within three months of January 1st each year.

(h) The Executive Committee (referred to below) has power to refuse applications for all types of membership. They must however in such event inform all full members of the reasons for such a decision at the earliest reasonable opportunity, and their decision may be reversed by a vote of full members. Similarly, the Executive Committee has power to expel members who in their view are acting contrary to the Policies and Constitution of the Union, where discussion has failed to resolve the matter. The member concerned is entitled to a written statement of the Committee's reasons for expulsion, and has the right of appeal through the Circular to a vote of full members.

4. Circular and General Meetings.

(a) Because of the dispersed membership, and mobility problems, the principal means of formulating and deciding policy will be a confidential circular which will be sent to all full, junior, and overseas members at least 4 times a year. All members except Associate members are entitled to have their views printed in the Circular up to a limit in a particular issue of a number of words to be decided from time to time. Proposals for changes in Union policy, or for major Union decisions, put forward by the Executive Committee or by 6 or more members in the Circular, will be decided by a secret postal ballot, with each full member having one vote. This vote is to be arranged by the Executive Committee as soon as practicable and in any case within no more than three months of a reasonable degree of discussion having been possible through the Circular on the proposal.

(b) All votes in the Union, including those in any Committees, will be by a simple majority of those voting. Such a majority may decide to hold a General Meeting which all full and junior members will be entitled to

attend. Notice of resolutions and any other business to be transacted will be sent to all full, junior and oversee e members at least 1 month beforehand, and arrangements will be made for full members unable to attend to vote by post if they so request. In the event of any dispute about voting, resolutions, elections or other Union business, the Executive Committee will have the right of decision, but if six or more full members wish a vote of all full members must be arranged on the point in question with three months.

5. Executive Committee.

(a) An Executive Committee of the Union will be elected annually, by secret ballot of all the full members if there is more than one candidate for a position. Any full member may volunteer or be nominated by another full member for a position on the Committee. In the event of vacancies occurring between elections, the vacant position may be filled by the Executive Committee co-opting a full member of their choosing. Any member of the Executive Committee may be removed from office at any time by the vote of a majority of all full members voting in a ballot called at the request of at least one fifth of all full members at the time.

(b) The Executive Committee will consist of: a Co-ordinator; a General Secretary; a Treasurer; a Membership Secretary; an Information Secretary (for disabled people); a Publicity Secretary; the Editors of the Internal Circular and the Open Newsletter; and four Regional Secretaries, that is one for Scotland, one for Wales and the West, one for the North and Midlands, and one for London and the South East.

(c) Members of the Executive Committee may speak and act officially in the name of the Union on the basis of the Union Policies and Constitution. Each Executive Committee member is personally responsible to the Union as a whole for the carrying out of the functions of her or his office, but as far as is practicable they will consult each other and act together as a Committee. The Committee as a whole is responsible for controlling Union funds and property, and for ensuring that proper books are kept and full account of Union finance is given at least annually to all members.

(d) The Committee will draw up guidelines for its own conduct, and the distribution of responsibilities between its members, for the approval of the Union.

(e) The overall purpose of the Committee within the Union is to facilitate the active participation and development of members in fulfilling the aims of the Union. The purpose of the Union is to offer help to members and other disabled people in our struggle to change the conditions which isolate, segregate, and oppress us.

Reply to [Member E]²⁸⁵ (1974)

On reading [Member E's]²⁸⁶ contribution to this Circular I felt it raised issues which are especially important in the Union just now, and she agreed that I could add a few points.

Up until now in the Union, we have been concentrating mainly on trying to get some of our basic ideas straight on disability. Rightly, in my view, the fears of disabled people in very vulnerable situations have not held the Union back from looking clearly at the problems of disability and proposing the kind of solutions we think necessary if real improvements are to come about. But now that a forward-looking policy has been adopted, the problem raised by [Member E] becomes very important and immediate. I think we must apply our basic principles to the task of working out ways to meet the problems which arise as we enter the next stage of our struggle. First among these problems is the one [Member E] raises – that of the vulnerability of some actual and many potential Union members. It is in the nature of our disabled condition that we are especially vulnerable to pressures from the authorities and other hostile people, and our Union will only succeed when together we find ways of tackling these pressures and the fears they produce. This is to me the essence of a Union – that oppressed people come together to defend themselves and change the situation which makes them so vulnerable. (I stress the mutual aspect of this. Some members will obviously start off more independent and less easily intimidated than others, and they can initially help a great deal when things are difficult for the more vulnerable. But this must lead to mutual help and growth in strength of all members if we're to make lasting progress. We cannot be content with a situation where some members simply become experts in helping the others, because inter-dependence, sharing skills, and helping each other to become active are the only ways in which the problems of disability can be overcome).

There was mention at the Policy Conference of the problems some people in institutions will face, and I was impressed by the suggestion, based on members' experience, that two things were particularly helpful. One was having visitors and outside support generally. The second was to try always to make any struggles collective. As a start this seems to me very sound advice. The Union must surely see to it, as [Member E] suggests, that anyone who is under pressure as a member receives all the support we can give – visits, letters, phone calls, offers of help. This is at the same time one way of making the struggle collective, as other Union members become involved in solidarity. Another way is to try always to gain support within a particular situation from people who are not Union members. This would apply outside as well as inside institutions, but the example that come to mind is Pearce House. Although many of the residents there were passive, there were some issues on which they felt strongly – they were prepared to risk joining with Maggie [Hines] and Ken [Davis] in signing a protest about the removal of a valued staff member²⁸⁷, for instance. The protest was also supported by some other members of staff and relatives of residents.

However, the building up of effective Union and other support takes time, and anyway it can't prevent hostility and the subtle and unsubtle pressures that we all face in varying degrees. I think that it is primarily for those who are themselves most subject to the particular pressures within institutions to suggest ways in which the Union can help them best. But the following points may serve to take forward the general discussion [Member E] has started.

1. People who feel particularly threatened could for a time quietly support the Union (by subscribing to the Open Newsletter, perhaps writing articles, or doing other work for us, etc) without actually becoming members.
2. It might be possible for some vulnerable people to become members at first under an assumed name (with their real name and address known only to the Membership Secretary who would act as 'post box' for them). They could contribute to the Internal Circular and Open Newsletter under their assumed name, and then in time as they became more involved could make personal contact with other members and so build up the confidence for more open activity.

3. People who do become members under their own name may still have no need to reveal their membership to the staff who look after them in an institution, for example, until such time as they decide they are strong enough to do so.
4. There is no need for vulnerable members to take on the more exposed Union committee positions, or to shout their membership from the rooftops. There will be plenty of quiet work to be done in the special interest groups, in the internal organisation, etc. When we are isolated and weak is not the best time to deliberately draw down hostility on ourselves.
5. When we are known to be members of the Union, we are bound to face not just genuine interest and criticism, but sometimes basically hostile questioning and being heavily 'leaned on' by certain kinds of people. In institutions there may be strong threats of victimisation, neglect, or even physical violence from some staff, when we are known to hold views which challenge their view of things. Each person will of course have to decide for themselves how best to handle particular situations like this when they are on their own, but I think there often a case for trying to avoid head-on confrontations. We may find we do get drawn into some situation where there is little choice except to argue, whatever the risks. But normally there seems to me every reason to avoid the provocation aimed at us by hostile people, whenever we're weak and may risk becoming demoralised by defeats. We should be determined, both as individuals and as a Union, to fight when and how and on what ground we choose, not when our opponents decide it is the time. As we develop, we will become increasingly able to tackle problems. We will also learn more about tactics, about the various ways of struggling most effectively – such as retreating when necessary. As individuals we will become better able to judge when we are on strong ground, and more able to take the offensive when we are in situation where we have Union support and/or that of other sympathetic people. On the occasions when we do find ourselves alone and being hard-pressed, we may be able to deflect our attackers by avoiding the issue they're trying to force, by saying we don't know all the answers (which is true) and so on.
6. A less threatening but still difficult situation may arise when such people as administrators, doctors, Management Committee

members etc, pick on an isolated member to attack the Union's policies. They may be very high powered, full of sophisticated arguments, they may go straight for our weak points, make personal attacks (chips on the shoulder and all that), they may distort things to try to get us away from the issue and on to minor details or major political points not mentioned in the Policy and so on. Again, it seems to me that we can find various ways of dealing with such people if we decide their approach is basically hostile to disabled people, but find ourselves alone and a bit uncertain. One way would be to say we take their criticisms very seriously, and it would be a great help if they would write them down for the Union to consider. And even if they won't do this, then it would I think be useful for us all to write to the Internal Circular about any discussions we've had, both those where our arguments worked well and those where we felt we had no answer. Other members may be able to help with counterarguments, or there may be a valid criticism which the Union should take account of in developing policy.

The above remarks and suggestions mainly apply to situations where we are isolated, under threat, forced to retreat or assume the defensive. But, of course, this is only one aspect, looking at the worst side and ignoring the best. It's true that in the short term our opponents do have real power to hurt us, and they may be very expert at putting people like us down. We will suffer some defeats as we learn from experience how to handle situations. But in the end, there is no doubt that we are the stronger, because we look to the future whereas they cling to the past. We know for certain that the future will bring greater independence, activity, and integration for physically impaired people as a group, as developments in science and technology produce the necessary basis for this advance. Those who try to hold the movement for integration back can do so only for a while, and events will prove us to be correct over and over again.

Finally, I suggest that as we go into this new situation of committing ourselves to a Union with a progressive approach to disability, we will find that there are two main aspects to the struggles we face. On the one hand, we'll undoubtedly meet intimidation and nastiness of various kinds. But on the other hand, we will also find many decent people who will

support and help us. We may discover that we lose some old friends who find they can't agree with our views – but at the same time we will be making new friends who will encourage and help us in our efforts. In the same way, the Union as a whole may be attacked by some of the more backward groups in the disability field – but we will certainly have allies amongst others.

If we intend to achieve anything at all worth having, it seems to me that we can't avoid the process of taking sides, of risking offending some individuals and groups as a consequence of joining together with others who share our progressive view of things. This is especially going to be true in the coming years in Britain, as the current national crisis affects all areas of life including the small world of disablement²⁸⁸. Groups will be forming and re-forming as people take up more sharply defined positions on questions like integration and the cutbacks on spending on health, social services, and education. The new M.S. Action Group²⁸⁹, the Disability Alliance (overtaking DIG?), the emergence of Action Groups both for and against the Invalid Tricycle²⁹⁰, are only the first signs of the kind of changes there are likely to be. Our Union itself is part of this process, all of which has its encouraging as well as its threatening aspect. If we are prepared to work hard on the detailed organisation and policies of the Union, and try to recruit other members who are also serious in their commitment to change, then we will become increasingly united and strong enough to move from the defensive to the offensive in the struggle to enable all disabled people to lead a decent life.

The Need for Discussion and Study²⁹¹ (1975)

In his article in Circular 3, Vic Finkelstein sketched a helpful general view of the conditions which have led to the formation of our Union. He said:

“...when people, such as ourselves, are oppressed the individuals in this condition are bound to try and defend themselves. At first this is likely to be isolated individuals who speak out for themselves and struggle to change their own circumstances. In time some of these people may learn to speak out for all the people who are similarly oppressed. Historical conditions, however, determine the development of a collective recognition that the oppression is not confined to oneself but is part of the oppression of a group. When these conditions are ripe this oppressed group begins to organise itself in defence. At first such organisations are bound to be ‘blind’ with vague aims and an unclear idea as to the source of the misery. Again in time, particularly with the awareness of the inadequacy of then earlier organisations, new organisations are formed with clearer aims”.

Vic went on to argue that “a major task” for the Union, which should be inseparable from the struggle for practical changes in society, should be to “clarify issues. We cannot, after all, effectively struggle against something if we remain unsure as to exactly what we feel is wrong”.

Events in the disability field since that article was circulated help to confirm the accuracy of Vic’s analysis. More and more pressure groups are springing up – for example, the MS Action Group, the Spinal Injuries Association, the Disability Alliance. The first two are progressive in that at least they involve disabled people becoming active, while the Alliance is backward in being basically a specialist’s organisation with no democratic involvement of disabled people. But these and all the other

new organisations are still vague and muddled in their approach, and they all reckon to tackle particular, isolated practical problems. Our own Union originally came into being in the same sort of instinctive, haphazard way, to help to do something about the specific problems of institutional living. But alone of all the organisations in the field we have had democratic discussions amongst disabled people to try to clarify the essential questions posed in the situation we wish to change. Instead of spontaneously rushing into action at all costs, with a vague idea of wanting to do something to help, we have tried to work things out more carefully, to understand what is going on so that we are more likely to do the correct thing. And as we've discussed the question of institutions it's become clear that they are only part of the problem of disablement in general, and that disablement itself can only be properly understood and tackled in the context of working for change in society as a whole. Our **Aims and Policy** statement are therefore more precise, coherent, and comprehensive than those of any other organisations in the field.

The Union has thus advanced sufficiently already to become, for the moment, the rallying-point for other people who are also concerned to overcome disability rather than accept it. Even at this early stage we should increasingly attract people who are disillusioned with the undemocratic, partial approaches of organisations. Of the major established organisations to which disabled people belong, DIG in particular appears to have become bankrupt. This is not simply because of lack of militant leadership, or much tangible success, but essentially because it has failed to involve its disabled members in the struggle to become more active and more expert on disability themselves. When DIG first started it had something of the character of a grass-roots organisation with potential for advancement, but the elitist, undemocratic tendency has largely dominated over the years.

A quotation from the DIG Westminster Branch Newsletter of June 1973 shows what ordinary members' general function is considered to be. According to the Chairman the chief aims of this large DIG branch are: "1. Fund raisings: a) to provide DIG HQ with money for their (NB!!) campaign for a National Disability Income; b) for branch expenses. 2. Lobbying MPs about DIG. 3. Recruiting more members". There seems no doubt that this clear statement typifies the approach of most other Branches, and shows the indifference DIG leadership generally now has towards its ordinary members. To be fundraising lobby-fodder is apparently the extent of our usefulness. When the history of DIG comes

to be written it will be possible to give many other examples of the leadership's condescending, undemocratic, charity-type relations with other members. There are, of course, differences between individual leaders, and one 'wing' is more progressive than the other. These differences are important to us when we try to help change things. But the basic, essential thing to get clear first is that the present DIG leadership as a whole makes no consistent attempt to involve disabled people.

Our own **Aims**, and our general approach to members, make a striking contrast to those of DIG. But as I see them the Union **Aims and Policies**, which we have now to promote and defend, are only a first attempt, a sketch, a good beginning. As we get involved in new forms of activity and expansion it is essential that we continue the hard struggle to discuss and study disability so that we come to understand our situation more thoroughly, to grasp the essential truths amongst the mass of initially confusing facts and ideas which confront us – to “clarify issues”, as Vic says.

In many ways the struggle to apply ourselves to careful discussion and study is more difficult than carrying out practical tasks (for example, typing out an article is easy compared with the effort of trying to work out what to say). But without continuing discussion and study our Union would be condemned to become just one more little action group niggling away at a small part of the problem of disability. We could be sure that other more advanced groups would soon arise to overtake and criticise us. The crying need at this time is not just for another spontaneous, confused, well-intentioned action group, even one which has advanced as far as we have. If we want to help disabled people as a whole to join together to struggle more consciously and consistently for integration and a decent life, then the essential task is to develop an increasingly scientific, objective approach to the question of disability. No other group is attempting this work, yet it is the key to advancement of disabled people at this time. Without a scientific understanding, however hard we struggle we will remain confused and dis-united, at the mercy of each 'new' theory or proposal put forward by the experts. We will always be weak when we argue on the basis of our limited personal feelings and experience, using the inward-looking subjective approach, and trying to generalise on this basis. As Vic showed us in his very important article in Circular 10²⁹², the outward-looking method, which directs our attention away from our subjective feelings and experiences, towards common

experience and the objective facts of the situation as a whole, is the only way we can be sure we are based on reality.

There is nothing in the least ‘academic’ about the kind of discussion and study I suggest we undertake. We have already established the Union as an organisation and there will now be increasing pressure on us all to be active in on-going practical struggles. Our discussion and study will be closely joined with this work which will test out our ideas; formed through study of past, practical experience, is new practice. The point is that we could so easily find ourselves spending all our available time on organisational tasks. This would mean neglecting the work of developing the theoretical tools which disabled people as a whole need so that they can therefore direct their own activity most effectively for change. The **Policy Statement** commits us to developing “increasingly clear guide-lines for action”. So long as we continue to see theory as essentially “guide-lines for action” – as a question of developing the tools for change – then we need not fear getting lost in pointless academic debate and abstraction.

If it is accepted that we need to develop our understanding of disability, it may still be felt by some members in the Union that this is something to leave to the intellectuals among us. I disagree with this completely. It is true that some members in the Union, as in all areas of life, are more advanced than others in some respects, have greater experience and wider knowledge, are familiar with more words, have had longer in formal education, etc. We have to start by accepting that this unequal situation is a fact. But the vital question is, how does this situation develop? Will it be in the backward direction of the few becoming increasingly expert while the rest become more confused and lag further behind? Or will it be forward, so that the further development of the more advanced members takes place in conjunction with the development of the Union as a whole, with all members learning from and teaching each other in a co-operative way?

In the history of DIG we can see the first, backward tendency asserting itself. A small minority of experts at the top (including some physically impaired people) have become more and more familiar with the complexities of the situation, negotiate on behalf of members, talk the same language as the government experts, have full access to information which they keep to themselves, etc. But the mass of members do not advance at all; they become more confused, not less;

they remain passive, bored, increasingly convinced it is all too complicated for them to grasp, that it's best left to the 'experts'. When the leaders do find time to speak to the members, or publish statements, it is only to talk down to them in a reassuring way, or to mystify with unnecessarily long words, pretentious phrases, and muddled arguments, while, with the best of intentions, putting forward to the government proposals which are objectively opposed to the interests of most of their members. (See, for example, DIG's **CANDI Policy Statement**²⁹³). The membership becomes more de-moralised and depressed. The leadership attends more and more interesting meetings and functions at the Houses of Parliament.

So far in the Union this kind of backward process – the ever-widening gap between sections of the membership – has not taken place. We have instead concentrated on discussion amongst all members, and on trying to draw in people who normally would not attempt to write anything at all for publication. This discussion has been an essential part of the development of those who started off with certain advantages. Instead of the few advancing at the expense of the many, and away from the attempt to involve everyone, on the whole the basic tendency has been for the general level of understanding in the Union to rise as a result of our discussions. It is sad that a number of people remained passive and/or have decided not to re-join at the moment. But our failures (which to some extent we must expect, since the very condition of disability involves passivity, isolation, difficulty in expressing ideas and analysing arguments, etc) should not be allowed to obscure our real achievements. The Circulars drew into discussion some people whose views had never before appeared in 'print', and they contain already a storehouse of discussion on disability which seems to be more advanced than anything existing elsewhere.

I regard the Internal Circulars as having an essential function in continuing these discussions which we have started to such good effect. If we look back through them two broad levels of contribution can be distinguished. There have been personal comments from people who are beginning to share their experiences with others, and in the process discovering connections and a common experience, to grasp more and more that we share certain experiences as a group, that disability is a social phenomenon. And there have also been some longer, more theoretical, articles which argued for and against particular views on disability in general. It seems important that this mixture should continue

– increasing involvement of more and more members in discussions of common experience, together with the advanced study and argument which is necessary in addition if we are to develop the correct general theory for the overcoming of disability.

Outside the Circulars, it seems important also to continue this same two-fold process in the Union. Whatever the lack of formal educational background, all members would be able to participate in informal discussions to try and understand the issues better. Apart from phone, post, and tape communication between individual members, it should be possible for groups of us to get together in the different areas to share experiences and perhaps base a discussion on a section of the **Policy Statement** or something from the Circulars. At the same time more and more of us need to be working, particularly in the Special Interest Study Groups, to collect information, to study what others have written on disability, to become familiar with the question (which is what becoming an expert really involves). This will mean writing articles which develop (and popularise) an objective, scientific, outward-looking approach to disability. This in turn will feed back into the more personal discussions, and the results back again into the general study.

Yet again the same kinds of work, at both the personal and the general levels, need to be carried on outside the Union as we discuss and share our approach with other disabled people and sympathetic able-bodied people. We should be keen to discuss the **Policy** with non-members, both informally and maybe at specially arranged meetings of local groups (e.g., the MS Action Group, or at a residential institution). In my view we should not just be trying to recruit members, but should regard serious discussion about the issues of disability, with people who are really interested, as a valuable learning situation and a worthwhile contribution in itself. Our approach is quite new for many people, and there may be various reasons why they will not be able to join us immediately.

In any case, sometimes the most helpful people in the long term will be those who argue most seriously against us at first. We should be glad to continue such discussion as long as progress is being made, and should also be continually looking for areas where we can co-operate with other disabled people while making any disagreements on matters of principle quite clear. And this discussion with non-members must also be carried on by more of us as we develop, contributing to journals, examining the

views of the 'experts', encouraging democratic participation of disabled people, etc (as, for example, Vic does in his Winter issue **Magic Carpet** article²⁹⁴).

These kinds of serious discussion and careful study of the facts of disability, which must progressively involve more and more members, seem to me essential if we are to avoid the fate of DIG. The struggle to develop a scientific approach to disability is one in which all members should become increasingly involved and active. Only in this way will we be able to make our maximum contribution to the struggle for the practical changes in society which will overcome the oppression of disabled people as a whole.

Correspondence With Sir Christopher Foxley-Norris²⁹⁵ (1975)

The Cheshire Home authorities have responded to our Policy etc with two letters as follows – with replies.

“Thank you for your letter of February, enclosing **Policy Statement** and **Constitution** of the Union of the Physically Impaired against Segregation. Our Chairman²⁹⁶ has written a long letter letting you know that we support your views, and I would just like to add that I feel you use the term ‘disabled people’, whereas I prefer the emphasis to be on people with a disability, and therefore there should be no segregation

Carmel Short²⁹⁷”

“Many thanks for your note dated 5th March. We will be replying to Sir Christopher’s letter when we have been able to consider it at length. In the meantime, we should like to respond to your personal point about the Union’s use of the term ‘disabled people’ rather than ‘person with a disability’. We agree with you that the person rather than the disability should increasingly come to the forefront, and our whole organisation is aimed at assisting this process. As we say in our **Policy Statement**, ‘First and foremost we are people, not “patients”, “cases”, “spastics”....’ etc. However, what we cannot afford to forget for one moment is that at present we are also disabled people – that is, we are in reality disabled

by the way society is organised to isolate and exclude us. The struggle to change this dis-abling situation must be firmly based on a recognition that it does actually exist at the moment. Only if we keep this basic fact clear will we find the right way to solve our problems. As we say in the **Statement**, this will involve ‘... changing our conditions of life, and thus overcoming the disabilities which are imposed on top of our physical impairments...’.

So, while we agree with you that ‘there should be no segregation’, we see the need for a long, hard struggle to move from the present position where unfortunately there is widespread segregation, to a situation where it no longer exists and we are therefore no longer disabled (that is, prevented from living a full life).

Yours sincerely, P.G. Hunt”

The second letter was received from the Chairman of the Cheshire Foundation Homes for the Sick, Air Chief Marshall Sir Christopher Foxley-Norris, G.C.B, DSO:

“Thank you for your letter and the for the attached **Aims and Policy** document.

Let me say at once that, both personally and as Chairman of this Foundation, I endorse your views about the need to de-segregate the disabled and handicapped and to incorporate them as far as possible into normal society. I say ‘as far as possible’ for I think you will agree that the very severely disabled will always need special care, just as any seriously ill person does to the extent that some will always have to be looked after in places other than their homes and, as you say yourself, there are some who prefer to be in places of special care. As a Foundation you will know that we are strongly opposed to the institutionalisation of such places and the whole concept of our Homes is that they should be just that – homes. We therefore insist on their being comparatively

small, with the minimum amount of rules and rigid routine; and with the maximum participation of residents in deciding how the home should be run.

We have been able to move at least the first step in this direction with the experiment of the Palace Road Flats at Tulse Hill²⁹⁸, where handicapped individuals are enabled to live with their own families in apartments and bungalows especially designed to cater for their disabilities. We admit however that the creation of special facilities where such families are grouped together itself involves some degree of segregation from the local society, and that this is basically undesirable, but the scheme was conceived more than ten years ago. If we can make further progress in this field, we should no doubt have different and improved ideas for the future.

The ideal, of course, is that not only living accommodation but all other normal facilities such as shops, cinemas, pubs, sports grounds, should be designed so that every member of society, including the disabled, can make full use of them. There is movement in this direction; but there is still a very long way to go.

As to employment, we also make every effort to ensure that those of our residents who want to work can work (not all of them do want to, of course). Such employment must also be as normal as possible (we must move away from basketwork and so on wherever we can), and consequently where possible the individual should go out to work like everybody else. If this is not possible because of the degree of disability, the work must be brought to the individual; but it must be worthwhile, constructive work, not just occupation for occupation's sake. We have been successful in this field in a number of our Homes.

I am sure we all have the same objectives and are basically aiming in the same direction. Any pressure from anyone to bring those objectives nearer is welcome.

Sir Christopher Foxley-Norris

(A draft of this reply was seen by all the members who are in Cheshire Homes, and it received general approval):

Dear Sir Christopher,

Thank you for your letter (5/3/75) of comment on our **Aims and Policy Statement**. We are glad to have your personal and official endorsements of our view on the need for de-segregation, and also your other comments. As we said in our covering letter, we regard such discussion of the issues as helpful, and we hope you will be prepared to extend this to the **Cheshire Smile** so as to involve Foundation residents, staff, and voluntary helpers in the process.

On the general question of segregation, we welcome very much your general agreement that all normal facilities in society should be designed so that everyone can use them. We welcome too your recognition that the Palace Road flats scheme involves a degree of segregation which is undesirable, and that any similar developments in future would need to be improved on. And your point that work opportunities should be as normal as possible is in line with our views also. In these parts of your letter, you appear to recognise the way things are changing in the field of disability, and to support a progressive approach to the remaining problems: as you put it, 'There is movement... but there is still a long way to go'.

Unfortunately, you do not seem to recognise this same movement in situation of the 'very severely disabled' people you write of, when you argue that they will 'always have to be looked after in places other than their own homes'. Our Union is unable to agree with you on this point. In our study of the situation, we have come across no evidence to support the view that there are any fixed barriers to the integration of severely impaired people. We see fundamentally the same process of development taking place, whatever the difficulty of the remaining problems. The whole history of disablement is one of progressive overcoming of limitations, and we see

no reason to suppose that this process is coming to a halt.
On the contrary, the signs are that it is accelerating.

As our **Policy Statement** points out, a good proportion of people with paraplegia, or who are blind, for example, are nowadays able to lead active lives it would have been hard to imagine not long ago. The members of the Association of Disabled Professionals²⁹⁹, the Disabled Drivers Association, the National Federation of the Blind³⁰⁰, the Spinal Injuries Association, and other similar organisations, not only provide a striking illustration of this integration process, but also show how it is being extended to include much more severely impaired people, such as those dependent on mechanical respirators. Our contacts in other countries make it clear that this movement towards integration is a fast-growing international phenomenon, and that in many respects other countries are more advanced than Britain.

It is developments in electronics which have, in particular, meant that it has become possible to effect a transformation where previously 'unsolvable' problems are concerned. For example, recent experiments show that devices implanted in the brain can begin to enable some blind people to 'see'.

Some previously unintelligible speech can now be de-scrambled by electronic means. Wheelchairs which can climb stairs, and devices which can fold a wheelchair and store it in a car, are being developed. Large vehicles can now be controlled simply by pressure from one finger. And so on. All this is in addition to 'primitive' devices, whose existence we are already coming to take for granted – Possum controls³⁰¹, electric typewriters, wheelchairs, and hoists.

Outside the field of aids like these we can see even more evidence of human ingenuity in tackling problems, and it is plain that research into aids for physically impaired people is only just starting to develop. Human beings on the moon are completely disabled – so much so that we would all die immediately in this hostile environment. Yet this enormous problem has been overcome in our time, and for us it is a lesson not to set our sights too low when deciding what is or is not possible. We note too that experts who work with even

comparatively low-level technology to solve our problems can see the potential opened up by these means. At the July 1974 REHAB International Seminar in London³⁰², P D Walters, a psychologist working with the Possum team, said: 'Every physically disabled person can be enabled to control their environment, become educated and employed. They can be independent, self-sufficient individuals. Theoretically? Yes. Practically? This will be the responsibility of Society'.

Where for the present some help with daily living activities is still required, in addition to electrical and mechanical aids, there is increasing evidence that this can be provided outside segregated institutions. It is known that for every person in an institution there are many more with equally severe impairments who live at home because they have a family or friends to help them. A well-known example of this is Hilary Pole³⁰³, said to be the most physically impaired person in Britain, whose only movement is a slight one in one toe. In Sweden and other parts of Europe, the Fokus Society (which was started in 1965) makes arrangements which completely replace or supplement this family help, in flats which are integrated into ordinary housing. The residents include a good proportion of people who need turning in bed at night, help with feeding, dressing, toilet, etc. Any medical services required are available in the normal way by district nurse and GP visits, with the hospital service available as it is to anyone else in case of illness. This confirms the importance of making a clear distinction between physical impairment, on the one hand, and sickness and illness on the other hand. Only when this distinction is thoroughly understood can our normal daily living arrangements be viewed correctly as essentially a social question, with medical care taking its proper subordinate place in the service of the whole human being.

We note that Dr. Agerholm, in her evidence to the DHSS sub-committee on rehabilitation in 1969, applies this distinction when describing the care residents in the Cheshire Homes require. She says: 'Few... require care beyond that which a family supported by a district nurse are known to be able to provide in the home'³⁰⁴. In our view, all this evidence, and a

great deal more besides, points towards the real possibility of integrated solutions to our problems, however severe the degree of physical impairment.

With regard to your statements on the Cheshire Foundation in particular; again, we welcome your opposition to institutionalisation, and we strongly endorse your insistence that Homes should be small, with minimum rules and maximum participation of residents in the running. However, we would make two points in this connection. Firstly, there appears to be great variation on the amount of consultation of residents in the various Homes. In a few they are represented on some or all of the committees which manage the Home. In most they are not even on one of these bodies, and in fact resident participation may be actually discouraged (as Audrey Shepherd's letter points out in the **Cheshire Smile**, Winter 1974³⁰⁵). Again, there are enormous variations in what is considered a minimum amount of rules and rigid routines in the different Homes.

Secondly, while we support all measures to help the residents lead fuller lives within institutions, in our view the process of institutionalisation is essentially the result of our exclusion from full social participation. It is isolation and segregation, whether or not in a Home, that causes the apathy, depression and rigidity of outlook which are commonly said to be characteristics of institutionalisation. It follows from this that it is only possible to combat this process up to a certain point while we remain in an isolated or segregated environment. The best way of all to deal with 'institutionalisation' is to move as quickly as possible towards the implementation of our Union's **Aims**: that is, '...to have all segregated facilities for physically impaired people replaced by arrangements for us to participate fully in society'.

We hope you will be willing to continue this discussion

Yours sincerely, Paul Hunt

[A] letter from Sir Christopher Foxley-Norris, Chairman of the Cheshire Foundation, was printed in the last Circular together with a reply on behalf of the Union. Below is his answer to us and a further reply from the Executive Committee. This reply was formulated in the Committee Circular, and the discussion is 4 foolscap pages long. If anyone wants to read it, each Committee member has a copy. As I saw it, the discussion was very helpful, and resulted in a greatly strengthened reply. My original draft both avoided tackling Sir Christopher straightforwardly about his “planning for these people” (see below) and fell into the trap of discussing solutions to problems with him over the heads of residents. The final letter is far more in line with the Union **Policy Statement**.

Reply from Sir Christopher Foxley-Norris:

Dear Mr Hunt... Thank you for your letter of 6th April. I quite accept your disagreement with my comments on the position of the very severely disabled. My mistake was in using the word “always” (your para.3 refers). What I had in mind was the foreseeable future in this country, and I should have said so.

Here again you will disagree, and you will charge me with over-pessimism, indeed defeatism. I could argue in return that I am being realistic and therefore prudent. Naturally I entirely accept the fact of technological advance, and the desirability of it providing a more natural solution to the problems of the severely disabled than residential care. Practically however, I have to face the fact that the finance to implement fully the technological advances in every case of need does not appear likely to be made available in this country in the immediate future: consequently, as Chairman of the Cheshire Foundation, it is clearly my duty to continue to plan for residential care of these people. If I am proved wrong, I shall be very pleased. As I said at Hydon Hill³⁰⁶ at our seminar this week: “We are not Empire building. If by the year 2000 it could be demonstrated that there was no longer a requirement for residential Cheshire Homes, everyone in the Foundation would be delighted”.

With this in view we are giving serious thought to every alternative to residential care; but we must keep the latter as an insurance position until we can progress fully into further fields. I am, of course, very willing to continue this interesting discussion.

Yours sincerely, Christopher Foxley-Norris, Chairman
(Cheshire Foundation Homes for the Sick)

Union answer:

Dear Sir Christopher....

Thank you for your letter of the 20th April. We are very glad to know that you accept the principle of technological advance providing the means for a more 'natural' solution to our problems than residential care. We regard this principle as of fundamental importance. It defines the problem of overcoming disability as essentially one of providing the means for us to participate fully in society. This gets right away from the confusing and depressing approach which incorrectly sees such things as 'prejudiced attitudes' or 'stigma' or 'lack of motivation' as the basic problem. It is useful to be able to leave these and other similar red-herrings and, having once agreed that technology provides the necessary means to integration, to concentrate then on the next vital point. This is to make available to disabled people the fruits of technological advance, so that we can 'live where and how we choose with full control over our lives', as the Union **Aims** puts it.

We regret that you do not follow through your acknowledgement of the possibilities inherent in technological advance by placing your influence behind the realistic and practical demand for severely impaired people to have the opportunity to make use of the facilities for integration which have already been developed. For example, all the means are already available to bodies such as the Cheshire Foundation to pioneer in this country facilities along the lines of the Fokus schemes, which we

referred to in our last letter. It really would be a positive step forward for the Foundation to help existing and potential residents to explore these possibilities fully, and to offer them greatly increased opportunities to live more integrated lives with secure background personal help. We stress that there is nothing 'uninsured', impracticable, or unrealistic about what we proposed should be offered to disabled people. The Fokus scheme started in Sweden 10 years ago, and has since spread to Denmark, Holland, and West Germany. As a minimum, similar schemes could be implemented in Britain – certainly within the 'foreseeable future'. The argument that Britain cannot afford such facilities is not valid, because in fact Fokus schemes have proved to be one half to one third cheaper than institutional care. Even allowing for possible differences in this country, it is difficult to see how Fokus-type provision could be more expensive. It also seems probable that providing modern aids and decent social services to people in their own home is in general cheaper than institutions, which are increasingly proving vastly expensive to build and run.

But even if these points of cost are left aside, it is surely a duty for all who seek the well-being of disabled people to oppose our dehumanising exclusion from full participation in society. In our view, bodies such as the Cheshire Foundation should be actively working and campaigning to involve disabled people in developing the secure non-institutional arrangements for our care which are so urgently required. When today such arrangements for greater integration are possible, as can be demonstrated conclusively, then we ask for active support and encouragement from our friends in pressing our entirely reasonable case for rapid progress. We can surely leave it to others to argue the case against change.

Finally, what we find most disappointing about your letter is that you do not appear willing to take the first practical steps towards increased participation of disabled people as far as the Cheshire Foundation is concerned. You do not reply to our point about the wide variation in the extent of resident participation in the different Homes, and the differences in

what is regarded as a minimum of rules. Nor have you responded to our request to promote discussion, of the kind we have been having, in the **Cheshire Smile**. Yet unless residents have full information about different views on institutions, and the possibilities available for alternative ways of living today, how is it possible for them to gain greater control over their own lives?

Your lack of response on this point is underlined when you say "...it is my duty to continue to plan for residential care for these people". It is precisely this way of dealing with other people's lives which pervades the institutional set-up. Our Union strongly opposes such an approach of planning and deciding for people over their heads. What we seek for residents in Cheshire Homes, as for disabled people everywhere, is that they should be helped to plan and control their own lives on the basis of the fullest possible information about alternatives. For this purpose, our Union would be glad, not only to take part in **Cheshire Smile** discussions, but also to participate in meetings with residents, along with other organisations, if they wish to know more about the various points of view on alternatives to institutions.

We are stating our views very plainly on the last fundamental question. You have come forward to help disabled people, and we therefore hope that your concern for us will enable you to see how important it is that the efforts of experts and other able-bodied people should be aimed at our taking an increasingly active share in planning and controlling our own lives. Yours, sincerely, etc etc....

Paul Hunt (on behalf of the Executive Committee)

The second exchange of letters between the Executive Committee on behalf of the Union and Sir Christopher Foxley-Norris, Chairman of the newly styled "Leonard Cheshire Foundation" (previously "The Cheshire

Foundation Homes for the Sick”) was printed in Circular 16. The following correspondence brings the exchange up to date (Feb 1976)

(30th July 1975) “Dear Mr Hunt – thank you for your letter of 18th July. You have written to me frankly and critically which I appreciate. I will reply in kind.

I am naturally fully aware of the Fokus and similar experiments, and of their proven merits. As to expense, it is of course indisputable that they should and do prove cheaper to run. But unhappily this is not the current issue. What is lacking in this country at present is the major capital for the needed build. I can assure that our sights are by no means exclusively set on traditional residential care. In proof of this, although you wrongly addressed your letter to me at “Cheshire Foundation Homes”, in fact at a recent Trustees’ meeting, when it was suggested that the word ‘Homes’ should appear in our official title, this was rejected because of our intention to provide other forms of care for the disabled.

However, I cannot escape your opposition to my statement in my previous letter that ‘it is my duty to continue to plan for residential care’. It must surely be obvious to you and your associates that we cannot immediately abandon such care for those now in the Foundation, at least until an alternative is available. And I would remind you that it is a proven fact that many of our residents do not want any alternative.

I cannot accept and indeed I resent your charge that I ‘do not appear willing to take the first practical steps toward increased participation of disabled people as far as the Cheshire Homes are concerned’. Indeed, I have just returned from chairing a two-day seminar at which this subject was under continuous and active discussion; and at which much of the talking, both set-pieces and the debate, was done by residents of our Homes. From your residual contacts with the Foundation at Le Court, you must surely be aware that we have already progressed far beyond what you term the first

practical steps. Increased resident participation is not only the policy of this Foundation, it is also its practice.

Nor is there any validity in your suggestion of 'planning and deciding for disabled people over their heads'. To disprove it, I would inform you that only last Saturday, our Trustees' Committee decided to allot a considerable sum for the sole purpose of conducting a professional survey among the residents of a single Cheshire Home to ascertain their precise and individual wishes as to their future accommodation.

In your letter of February 1975, you state that your Union 'does not claim to represent or speak for other disabled people'. If I may say so, you also appear unaware of the amount and direction of much of what is being done and planned for such people. Just because you are not directly participating in such work, you should not assume that it is non-existent

Christopher Foxley-Norris

Union Response

(25th October 1975) " Dear Sir Christopher – Your letter dated 30th July has now been carefully discussed by the Executive Committee, and I am directed to send you the following reply.

Your letter raises two issues of vital importance which we will deal with first.

(1). We are extremely interested in your statement that it is "a proven fact that many of our residents do not want any alternative". This is a very serious statement about the lives of what you are presumably suggesting is a large number of people, and it cannot be allowed to stand unless it is substantiated by hard numbers. We ourselves as a Union, in our careful study of the situation, have come across no

evidence whatsoever to support your claims. We should therefore very much like to have details from you of your proof so that we can study it in the Union. However, we should point out that for you to make such a statement without also being able to give the evidence which makes it a “proven fact” would be lacking in responsibility and could be seen to be an abuse of the trust residents may place in someone in your authoritative position.

(2) In the second paragraph of your letter you also clearly suggest that our Union has been asking the Cheshire Foundation to “immediately abandon” the residents in the Homes. This is a most surprising distortion of our clear policies coming from a person who is Chairman of a major Trust in the field of disability and who has had every opportunity to become familiar with such issues. The extraordinary words you have chosen to describe our supposed views are entirely yours. Nowhere in the whole of our Union **Aims and Policy Statement**, nor in our letters to you, will you find the least suggestion of our wanting to “immediately abandon” anybody. Our real position on institutions is set out very clearly in the **Aims and Policy**, and it is applied to the Cheshire Foundation in our letters to you (especially in paras 7 and 8 of the first letter, in paras 2-5 of our second). In fact, your suggestion that the Union advocates that the residents should be abandoned is a particularly flagrant misrepresentation of our carefully thought out views.

(3) In addition to these two major points, you raise a lot of other issues which we will now deal with as briefly as possible.

(a) The last paragraph of your letter makes the defamatory assumption that our Union members are “unaware of the amount and direction of much of what is being done and planned” for disabled people, and that we are not directly participating in such work. It is arrogant of you, as an individual, to make statements like this about an organisation of physically impaired people of which you are clearly ignorant. Our Union combines the vast experience of people

who have many years of personal and professional involvement in disability and who are directly participating in many different projects and organisations. We are extremely well aware of the most advanced thinking and practice in this field, and it is in the light of this high standard we are helping to set that we have criticised your out-of-date approach as shown in your letters.

(b) When we criticised you for writing that it was your “duty to continue to plan for residential care for these people” it was perfectly clear from the context that we were objecting to you designing and planning without involving the residents in the process. You have still not answered our point that it is precisely this way of dealing with other people’s lives which pervades the institutional set-up. In fact, you blandly repeat your error where you write of “what is being done and planned for such people”. Nowhere in your blindness on this vital point more plain than when you attempt to “disprove” our suggestion of your “planning and deciding for disabled people over their heads”. You inform us of the Trustee Committee’s decision to allot a “considerable” sum for conducting a professional survey of opinion in one Home. As you have described the decision, with no mention of the residents’ involvement, it is in total contradiction of your claim not to be deciding things over disabled people’s heads. What we should like to know is whether or not residents’ elected representatives were amongst the Trustees who took the decision to spend the money, and if Foundation residents as a whole also participated in choosing the priorities for expenditure of this “considerable sum”? If this was the case, then the Foundation has indeed made a real advance towards fulfilling the second half of your statement: Increased resident participation is “not only the policy of this Foundation, it is also its practice”. But if residents were not closely involved in this way, then your announcement proves our point that you continue to make decisions over disabled people’s heads.

As far as the decision to pay for a survey of residents’ “precise and individual wishes in one Home” is concerned, we regard it as an admission of failure on behalf of the

Trustees. Opinion surveys are notoriously unreliable, and the results depend very much on what questions are asked, by whom, and in what context. Whatever facts are collected still have to be interpreted, and there are always conflicting views to what they mean. In any case, when residents eventually see the results, they will find that paid experts have been asking them questions in order to produce a report telling them more or less accurately what they said and were thinking some time ago. The calling up of experts to mediate between the Trustees and residents is no substitute for helping residents to organise together to put forward their own views directly, and participate in making such decisions as to whether or not to spend money on employing experts, and if so, in what capacity.

(d) You have made an incorrect assumption about our statement that you “do not appear willing to take the first practical steps towards increased participation of disabled people as far as the Cheshire Homes are concerned”. A glance at the context makes it perfectly clear that we are referring to the practical points made by the Union in this correspondence. What is significant is that you have raised a barrage of argument against a far-fetched interpretation of our actual statement, [...³⁰⁷]. To these must be added a third. You have completely ignored our offer to participate in meetings with residents who want to learn more about different views on alternatives to institutions.

(e) We welcome your acknowledgement of the “proven merits” of the Fokus scheme, and of the fact that they appear to be cheaper to run. We take this together with your earlier recognition of the “fact of technological advances providing a more natural solution to the problems of the severely disabled than residential care”. What we understand you to mean by these statements is that schemes along the lines of Fokus are both cheaper to run and offer a fuller life than a residential institution. It is therefore very strange that you give up at this point and pessimistically say “...unhappily... what is lacking in this country at present is the major capital for the needed build”. When someone in your position first of all acknowledges the possibility of major improvement in the

lives of severely handicapped people, but then immediately rules out all present chances of introducing those improvements, we need to look very carefully at the reasons given. Your statement that the capital is lacking in this country is demonstrably untrue. We are all familiar with the kind of capital sums which are at present being spent on weapons, and on prestige projects, and on new institutions, for example. What this proves is that the capital is not unavailable, as you maintain, but that it is available for some things and not for others. You evidently see no point in fighting to change this de-humanising order of priorities, and you ignore our request that the Cheshire Foundation should actively work and campaign for the alternatives we need. Fortunately, not everyone shares your defeatist attitude towards the urgently needed improvement we, as a Union, are struggling for, and so we remain optimistic that success can be achieved in the “foreseeable future in this country”.

(f) The recent change in the Cheshire Foundation’s name, of which you inform us, cannot be “proof” of anything except that you have changed the name. In any case, it is completely unhelpful to the point you try to make in paragraph two of your letter, since it has never been any part of our argument that the Cheshire Foundation was “exclusively set on traditional residential care”. It would however be less misleading if your letterheads reflected this change in your official title.

(g) Finally, we emphasise once again that we are very anxious that residents in the Cheshire Homes should have the opportunity to know what you and we are saying about them and the possibilities of major improvements in their lives. For example, we think residents would be interested to know that the Chairman of the Foundation accepts in principle that schemes along the lines of Fokus are both cheaper to run and offer a fuller life than a residential institution. We stress again our offer to participate in meetings and printed discussion for the purpose of giving residents full access to information about the different views of alternatives to institutions.

Yours sincerely, Paul Hunt, Secretary of the Executive
Committee

Notes on the Cheshire Foundation³⁰⁸ (1975)

[I]n my view, the Cheshire Foundation itself never was a pioneering venture. All the genuine pioneering had been done in the first 2-3 years, before the Foundation run by Trustees ever came into being. In these very earliest days, the really pioneering aspect was that the community at Le Court had few divisions between residents and staff, there was little medical emphasis and control, and residents took a big share in administration (one was Treasurer, for example). In all this it was the residents and helpers who did the 'caring' in a co-operative way together, building on what remained of the tradition from a co-operative post-war farming community which Cheshire had helped to start but which had collapsed³⁰⁹.

When the Cheshire Foundation was established as a registered charity, and Trustees took control, it was on an institutional, authoritarian, medically dominated basis. Residents were excluded from active participation, repressive rules were introduced, residents began to be threatened with expulsion (and sometimes were expelled) etc. All this was with the full approval of Cheshire, who had by then lost what democratic 'pioneering' spirit he once had, and concentrated his own and the Trustees' efforts almost exclusively on increasing the number of Homes while branding as selfish all who thought the quality of life in the Homes was also important. The Cheshire Foundation throughout the whole of its existence has been characteristically opposed to resident participation, abolition of uniforms, relaxation of rules, etc. In all the struggles of residents (with some helpers) for a better life, the Foundation led by Cheshire has been indifferent or positively repressive.

Some individual Trustees have in recent years sometimes talked about implementing a few of the measures advocated by residents for years past, and occasionally something happens. But they usually don't acknowledge the source of their bright ideas (i.e., disabled people). And

when they do, it may not mean much. Another 'progressive' Trustee, Dr Margaret Agerholm, acknowledged as long ago as 1964 that disabled people usually have the best ideas in rehabilitation. But if this is so, then the obvious conclusion is that disabled people should be helped to take control and so be in a position to implement their good ideas. But what has Dr Agerholm ever done in the Cheshire Homes, for instance, to back up what she's said? Another indication of how necessary it is to distinguish between words and deeds as far as the Trustees are concerned is their recent decision (taken at a think-tank weekend from which all residents were excluded) not to have a resident on the Trustees – while at the time Sir Christopher is talking to the Homes to get on with resident participation.

So, I think it can be shown, with ample supporting evidence if required, the Cheshire Foundation Trustees have characteristically opposed real care in the Homes, while priding themselves on doling out 'care for the disabled' in the old patronising way. (They have always refused to change the title from Cheshire Foundation Home for the Sick). So, to state that they have 'pioneered in the care of the disabled' is true only in their sense, but not in ours because we know what real care is about (...)

All this means that if the Cheshire Foundation does create Fokus-type schemes (with resident participation built in from the start) this would not be the 'next stage' as [some members suggest]. It would be the opposite of their characteristic approach. They have never built on the only real pioneering – resident and staff participation in community activity and decisions for one brief period at the start. It is only residents and a few helpers who have ever really pushed forward with this approach, and so been true to the best aspects of the original venture.

Correspondence with Professor Peter Townsend³¹⁰ (1975)

Over some years I've had very occasional contact with Peter Townsend (Sociology Professor at Essex). When he started the Disability Alliance he asked me to join on a personal basis, but I declined on the grounds that their basic approach didn't match up to some principles I'd developed through discussions in DIG. However, when the Union's **Policy** was published, I sent him a copy asking for any comments. The following letter came back:

Dear Paul.... I cannot remember whether I have yet thanked you for sending me a copy of the **Policy Statement** and **Constitution** of UPIAS. I fully support all your objectives and have written to the Membership Secretary to become an associate member. I hope the Union will feel free to become the watchdog of all disability organisations as you suggest in a final paragraph. I see the Disability Alliance as serving the function of political education, and because its resources are minute, it has got to employ all the expertise it can muster. We are still raising the funds for a full-time organiser, but think we can maintain a reasonably vigorous battle for a year. I would not choose to try and concert 35 organisations. It is something of a political experiment. I am under no illusions about the deadening hand of charity. New attempts to cut across political boundaries can have a generally radicalising effect, and disconcert those who think they are in entrenched positions. We will try to back you in public and will refuse to interfere with your independence. I enclose a copy of our intended policy statement and would welcome any comments. We hope to revise it within the next fortnight and make it the basis of a new campaign.

Yours ever, Peter Townsend

The Disability Alliance: The DA is an alliance of organisations and individuals. The organisations represent, or have special concern for, disabled people and include those which have been campaigning for many years for an adequate State Income for the disabled. The individuals include paediatricians, geriatricians, academic and other professional workers in community medicine, community welfare and social security and workers in research on disablement.

Statement of Aims: 1. The principle aim of the Alliance is the payment of an adequate income by right, as a matter of urgency, to all disabled persons. This income would depend on three principles: a) equity with non-disabled people – the income would bring the standard of living of disabled people up to that of the non-disabled, meet the additional expenses of disablement and afford special protection from the erosion of living standards at times of inflation; b) equity among disabled people – persons with different types and causes of disablement, whether their disablement is physical or mental, static or progressive, whether they have been disabled from birth or in war, industry, the home or on the road, would have an equal right to the same adequate income; c) equal benefit for actual degree of disablement – benefit would be paid at agreed rates according to the assessed degree of disablement.

2. The Alliance will advocate the rapid development of supporting services for disabled people in the community.

3. The Alliance will seek to inform the public, politicians and Government about the needs, circumstances, and views of disabled people, especially on living standards and the distribution of national resources for income and services. The Disability Alliance has come together because of the sense of urgency created by the current rate of inflation. In times of economic crisis, the people most hurt are the disabled.

If this statement is taken in conjunction with Townsend's letter, he would appear to be in opposition to the Union's policy. It's perhaps not easy to see this first, because some aspects of the Alliance seem good and it's hard to sort out which ones are the essential ones. In its favour,

the Alliance is more militant than DIG; it has drawn in some of the most progressive people who wanted change within DIG; it tries to unite many elements into one spearheading group (but on what basis?); its income proposals may be more comprehensive than DIG's; and it advocates rapid improvement of community services. The fact that the Government is apparently trying to snub the Alliance and negotiate with DIG may also seem a point in its favour. But the vital fact remains that the Alliance perpetuates and makes even more explicit DIG's crucial policy error of ploughing the incomes issue in isolation from the whole question of understanding and overcoming disability, and therefore like DIG (increasingly) sees no need for the democratic participation of disabled people. When an organisation's policy shows that they view income as the key to the problem of disability, which is therefore solvable by bigger government hand-outs, then the logical thing is to rely on all the experts available, with disabled people assuming only a minor or secondary importance. Instead of building on what remains of the progressive aspects of DIG, the Alliance has created an organisation which takes as its basis the key weaknesses (the concentration on finance and consequent lack of interest in involving disabled people). The Union's **Aims**, by contrast, place financial help firmly in the context of all the other changes in society required in the struggle to achieve full participation (that is, overcome disability) and therefore sees disabled people's active democratic involvement as essential.

After a few slight suggested amendments to the original draft reply to Peter Townsend, the following was then sent:

Dear Peter...

Your letter of 3rd April has now been discussed by the Union Executive Committee and we have agreed the following reply. The detailed income proposals of the Alliance which you sent would require too much time for a thorough analysis at the moment, but we hope they will be considered by a Union Special Interest Group on incomes in due course. However, we feel that some very important points are raised by your letter and the (draft) **Aims of the Alliance** sent earlier. In certain respects, which we detail below, these appear to conflict with your associate membership of the Union and your welcome statement that you fully support our objectives. We should

therefore like clarification of your position on the following points.

Firstly, the Union **Aims and Policy Statement**, which was very carefully discussed and which all members agree to accept, says on page 3 under the heading The Right Kind of Help:

“...the basic problem we face is our exclusion from full social participation. It follows that this oppressive situation can be put right only by disabled people actually taking a more active part in society. The efforts of professionals and other able-bodied people are therefore really constructive only when they build on and encourage the self-help and activity of disabled people themselves.... problems will be correctly tackled precisely to the extent that we all as disabled people become involved and active in our own rehabilitation”

Applying this clear Union perspective to the Alliance, the immediate conclusion follows that the Alliance is not tackling our problems correctly and is not really constructive – since it apparently sees no need to build up mass active participation of disabled people in the solutions to the problem of disability. As a Union, since we regard our exclusion from full social participation as the basic problem we face, we must regard democratic involvement of disabled people as essential to any real advance. The Alliance therefore seems a backward step even compared with DIG. Both DIG and the Alliance seek better incomes for disabled people, which of course we support, but in DIG’s favour additionally is the fact that at least its membership is open to disabled people and in this it still retains something of its original democratic potential.

As we see it, the crucial failing of DIG policy has been to continue to see the issue of finance in isolation from the whole question of understanding and overcoming disability. Because financial help is seen out of context like this, the question of democratic involvement of disabled people comes to be seen as increasingly irrelevant, and is never pursued consistently. The Alliance has carried over precisely this basic weakness of DIG, in both policy and practice. Whenever an organisation views Government hand-outs as the most important way of tackling disability, then the logic is to rely not on members but

on all the 'expertise' available – a backward trend in DIG which the Alliance has made the starting point for its approach.

In clear contrast, the Union's carefully considered **Aims** place financial help firmly in the context of all the other changes in society required to achieve full participation, and so overcome disability, and we therefore see disabled people's active democratic involvement as vital. From the Union point of view the answer to DIG's fundamental weakness must be more participation by disabled people, not less, and on the basis of a policy which recognises disability as a social question which by definition requires active participation by disabled people for real progress to be made.

Secondly, there are parts of your letter which also suggest an approach to disablement which is contrary to the Union's **Policy Statement**. You say that the Alliance's resources are minute, so "it has got to employ all then expertise it can muster". This contrasts with the Union's approach, because although our resources are also minute, we are extremely concerned about the kind of expertise we employ. We reject the kind of experts and professionals who do not "...build on and encourage the self-help and activity of disabled people...".
Such people can only hold us back.

We are also unhappy with your statement: "I would not choose to try to concert 35 organisations. It is something of a political experiment". We do not welcome 'political experiments' being made without control being in the hands of disabled people whose lives the experiment will affect. What the Union seeks is greater control by disabled people over how our lives are led and over what is said and done in our names. The statement that you "would not choose" to concert 35 organisations presumably means that in your view there was no alternative once you had decided DIG's inadequacies could not be remedied internally. But as we have argued above, in the Union's view the progressive alternative must be a wider view of disability and greater democratic participation.

Your letter says you are "under no illusions about the deadening hand of charity". This seems difficult to square with the attempt to form so many charities into an effective Alliance.

If charity is a dead hand, then why try to use organisations which are heavily under its influence to generate a 'radicalising' approach to disablement? Would it not be more logical to break with the old reliance on charity and create instead an independent organisation which relied primarily on the self-help and activity of the people most concerned?

You say you hope the Union will 'feel free to become the watchdog of all disability organisations'. The final paragraph of the **Policy Statement** says the Union aims "to ensure that all the organisations concerned with disability become fully democratic and responsive to the real needs and wishes of disabled people". Once more the question arises, how far can the Alliance be said to meet these points?

And one final related point. Your letter says the Alliance is serving the function of "political education". But we need to ask, what kind of education of what groups? The people actually involved in the Alliance are specialists and leaders of organisations. Once again, by contrast, the Union's approach is to try and help the people who have the greatest interest in change to become active and involved in taking up issues for themselves. We hope very much that you will reply to these comments as soon as you can. What we then intend to do is to print any correspondence in the next Union Internal Circular so that all members can participate in forming Union policy towards the Alliance.

Yours sincerely, P.G. Hunt (for the Executive Committee)

Peter Townsend then replied (paper headed The Disability Alliance, 96 Portland Place, London, W1)

Dear Paul.... Thank you for your carefully composed letter about the Disability Alliance. You raise a lot of extremely important points and, before committing pen to paper, I wonder whether it might not be best to arrange a meeting between a few members of your Union and a few representatives from our Steering Group? There may be misunderstandings on both sides, and it would be good to talk about them directly. If, after

that meeting, you would like me to reply formally in writing, for the purposes which you suggest, I would be glad to do so.

We have been able to make some use of a conference room at 12 Park Crescent, near Great Portland St Station, and I wonder whether you would be able to meet there later this month, say on Thursday 24th or Friday 25th July?

Yours sincerely, Peter”

“Dear Peter.....

As we mentioned in our last letter the Executive Committee intended to fully consider your letter of 7th July. The Committee has now completed its discussion and we have agreed the following reply.

Firstly, as you know, the Union has been meticulous in preparing its policy and aims. After 18 months discussion we reached agreement regarding our basic conception of disability and the necessary organisational requirements that we considered met this situation. In this respect it was important to us to clarify our understanding of the role and nature of other organisations and those questions were fully considered. In the absence of further information, we see no reason to suppose that our painstaking application of our policies to your letter may have led us to any ‘misunderstandings’. As you acknowledge, our letter was ‘carefully composed’. This was precisely because it is the fruit of 18 months hard work by all our members.

Secondly, as you will no doubt have seen, the policy explicitly welcomes co-operation and hence discussion with other organisations. This, however, must be on a principled basis. Our analysis of the inadequacies of previous organisations has led us to the conclusion that the correct way for disabled people to advance their struggles is by thoroughly analysing our situation and carefully planning for the future. We therefore cannot accept meetings with other groups unless there is prior agreement about certain fundamental principles, on the

purpose of the meeting and the conditions under which it takes place. In our opinion, the correct basis under which the Alliance and the Union could mutually discuss problems, would be the following:

1. Fundamental principles on which discussion is to be based: Disability is a social condition which requires for its solution (a) that no aspect such as incomes, mobility or institutions, is treated in isolation (b) that disabled people should, with the help of others, assume control over their own lives (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people.
2. Purpose of meeting: (a) to consider ways in which disabled people can become more active in the disability field and (b) to consider and extended programme of action to involve disabled people in discussions about their own affairs.
3. Conditions of the meeting: (a) there should be equal numbers or representatives from the Alliance and from the Union, up to a maximum of four each (b) the number of observers from the two organisations should also be equal (c) both organisations will seek maximum publicity about the results of the meeting to bring it to the attention of as many disabled people as possible and (d) the proceedings should be tape recorded and made available for disabled people.

We hope the Alliance will join with us in the forefront of the struggle with disabled people and will find that it can agree with our fundamental principles and other proposals. On the basis of a mutual agreement, we could then arrange a date and venue.

If our principles and proposals are not acceptable to you perhaps you would put forward alternative views which we would welcome for further consideration.

Yours, etc”

Active Social Participation Essential for Handicapped³¹¹ (1977)

Britain today has the necessary advanced technology and knowledge to bring physically impaired people into the mainstream of life and enable us to contribute fully to society. However, these resources are not generally used to solve basic human difficulties such as ours, but are instead mis-spent on sophisticated weapons for destruction or on luxury projects like Concorde, for example. There is therefore an ever-increasing gap between, on the one hand, the exciting technological potential which could transform our lives, and on the other hand the failure to make these means for full integration available in a systematic way for the vast majority of physically impaired people.

It is these two facts which underlie the mushroom growth of a great variety of 'disability' organisations and agencies in the last fifty or so years, as physically impaired people and our relatives have experienced, along with certain improvements, an increasing discrepancy between what could be and the grim reality of our continued isolation, segregation, poverty, poor housing, inferior education, massive unemployment and so on. In consequence we, and those who have sought to help us, have struggled for improvement not only as individuals but also by getting together in groups to exert pressure on government agencies, and perform charitable rescue work.

Of special significance is the emergence in the last 10 years of many self-help, 'consumer' groups whose leaders are drawn from that section of physically impaired people which has had most access to the new means for social participation. The urge to start organisations under our own control arose from the failure of traditional charitable groups to respond appropriately to the new possibilities for integration. Although these organisations continue to dominate the field, and similar ones continue to be founded, there can be no doubt that charitable agencies run for us do not meet our real requirements. The reason for this is

emerging more and more clearly from the struggles taking place in the 'disability world'.

In the past it has been assumed by the medical profession, and virtually unquestioned by anyone else, that the defect in an individual's body causes him or her to be unable to work, attend an ordinary school, take part in normal leisure pursuits, etc. This connection between impairment (the bodily defect) and disablement (the restriction of, or exclusion from participation) was a close one before the means to integration for everyone had been developed. But now that full integration has become possible, it is clear that the cause of disability is not in the individual's bodily defect. The cause lies in a form of social organisation which fails to make available the already developed means for the full participation of people who have physical impairments.

The significance of this is that since our active social participation is the essential requirement for the elimination of disability, there is no way this can be achieved for us by doctors, or other professionals, or voluntary workers on our behalf. Their role has to become a supplementary one, while we have to learn to overcome the passivity which our isolation and segregation impose on us. One indispensable way of doing this is by participating actively in organisations which represent our interests, thus entering into ideological, political, and social struggles, the outcome of which will determine what kind of social arrangements will be made available to meet our difficulties. In this way we can raise our level of involvement from that of merely personal experience to the general, objective approach in which we become our own experts.

The importance of this process was strikingly illustrated in November 1975 when the Union of the Physically Impaired Against Segregation met the Disability Alliance to discuss "Fundamental Principles of Disability". The Alliance, an umbrella organisation of a number of 'disability' groups, takes the position that the obtaining of cash allowances for disabled people from the state 'as of right' should be the main focus of struggle. The Union argues that the solution to our impoverishment is above all our participation in normal working life and all flows from this. State financial and other help must be geared to this end, so that we can earn a living and contribute to the common provision for retirement, periods of sickness, etc.

Two quite different and opposed conceptions of disability are emerging here. For too long the prevailing consensus has been that 'more should

be done for disabled people'. This 'more' has included many things which create disability, such as the wrong kind of cash allowances, or segregated institutions, or more special schools. The breakdown of consensus marks the beginning of our real emancipation.

Settling Accounts with the Parasite People
A Critique of A Life Apart by E.V. Miller & G.V. Gwynne
(1979)

Two Perspectives

"Britain today has the necessary knowledge and the advanced technology to bring physically impaired people into the main-stream of life and enable us to contribute fully to society". These are the opening words of our Policy Statement published in 1975. In a later section we contrast this exciting potential for integration with the grim reality of the conditions which characteristically exist in segregated residential institutions for disabled people. We go on to say that the best efforts of staff in such places "are systematically overwhelmed by the basic function of segregated institutions, which is to look after batches of physically impaired people - and in the process convince them that they cannot realistically expect to participate fully in society and earn a good living. This function was generally appropriate when special residential institutions first came into being, since in the competitive conditions of the time many physically impaired people could not even survive without their help. But now ... the need for segregated institutions no longer exists in the way it did. They have become seriously out of step with the changed social and technological conditions of Britain today".

This Union assessment has been confirmed in the years since our Policy Statement was first published, On the one hand, further evidence has accumulated of the cruelty and deprivation which institutional life involves³¹². On the other hand, there has been the rapid development of micro-processors and other technological aids with tremendous potential, both for solving specific problems associated with impairment, and accelerating the need for the reorganisation of society along lines which make "employment and full social participation... accessible to all people, including those with physical impairments"³¹³. There are also the continuing achievements of particular experiments which move towards more integrated living arrangements, involving personal help from the

community, such as the Grove Road project³¹⁴. Instead of physically impaired people having to adapt to an hostile environment, the means now exist to create a physical and social environment that takes account of the needs of people with physical impairments.

The conclusion which follows from this assessment is that segregated residential institutions are essentially oppressive under modern conditions, and that they should therefore be phased out and replaced by secure, integrated living arrangements in which severely impaired people would be able to participate fully in society. Looking at our situation from the position of an oppressed group, we in the Union are enabled to view reality objectively, recognising the potential that has now been made possible and by contrast the oppressive conditions of life that we are forced to put up with. The important thing is that our approach maintains a scientific analysis of our situation, which examines segregated institutions objectively within the context of modern social developments, is both necessary and possible. This positive perspective is in sharp contrast to the pervading view of the vast majority of politicians, civil servants, managers and “experts” connected with our lives. Blinkered by their vested interest in the continuation of the traditional segregating practices and institutions which disable us, they hold the view that severe impairment often makes “residential care” a regrettable necessity when there is no supportive family available – and similarly that integrated employment and education are just not possible for many of us because of our problems. As the gap widens between this out-of-date view of theirs, and the reality that it is they who are the main problem now that the means of integration are at hand, increasingly they have to find new ways of controlling or diverting the struggles which arise in different forms in connection with segregated institutions. One of the most important means of plugging this credibility gap is the development of increasingly sophisticated “explanations” to convince everyone concerned that some segregation will always be necessary, given the enormous problems posed by our defective bodies and/or minds, shortage of funds, public attitudes and so on. This is the underlying message even of those politicians who sometimes appear to be all in favour of integration³¹⁵.

There have been a number of publications in recent years which attempt, amongst other things, to reconcile physically impaired people and our friends to the continuing existence of segregated institutions. Examples of these are the Warnock Committee report³¹⁶ on special

education; the Snowdon Committee report on integration(!)³¹⁷; and the long introduction to Selwyn Goldsmith's book **Designing for the Disabled**³¹⁸. But probably the most influential publication so far has been **A Life Apart** by Eric Miller and Geraldine Gwynne of the Tavistock Institute of Human Relations. First published in 1972, their book was reprinted as a paperback in 1974 and adopted as one of the only four set books on the Open University course "The Handicapped Person in the Community"³¹⁹. **A Life Apart** is also widely used on training courses for social work and health work students. Yet, as far as I can ascertain, the only critique of the book that has appeared anywhere is one I wrote for the magazine of the Cheshire Homes in 1972³²⁰. Despite the strong criticism my review contained, it is clear now that I failed to tackle adequately the essential issues raised by Miller and Gwynne's work, and this article is intended to remedy that omission.

Miller and Gwynne's involvement with segregated residential institutions first started in 1962 at the request of several residents, of whom I was then one, at the Le Court Cheshire Home in Hampshire. We were at the time struggling for representation on management to extend the range of control over our lives and prevent the reinstatement of infringements of our individual liberty as expressed in such freedoms as, to choose our own bedtimes, drink alcohol if we chose, freedom for the sexes to relate without interference, freedom to leave the building without having to notify the authorities, etc. All of these had been hard-won extensions of control over personal life. We had thought, naively, that "experts" on "group dynamics" like Miller and Gwynne would be likely to support (and promote elsewhere) our struggle to build a community life in which residents took a really active part and shared in decision making. As is still the case today in every institution where the same struggle for participation continues, we needed every bit of help we could get. Resulting from our request, in 1966 Miller and Gwynne were financed by the then Ministry of Health to do a part-time pilot study lasting three years. During this period, they visited 22 institutions; did in-depth interviewing of people in 5 of them; carried out some "action research" at the Le Court Home; and held some discussion groups in London for the administrators of various Homes and Units.

Long before publication of their research findings in **A Life Apart** in 1972, it was clear that we, the residents, had been conned. It was clear to us that Miller and Gwynne were definitely not on our side. They were not really on the side of the staff either. And they were not even much

use to the management and administrators. They were in fact basically on their own side, that is the side of supposedly "detached", "balanced", "unbiased" social scientists, concerned above all with presenting themselves to the powers-that-be as indispensable in training "practitioners" to manage the problem of disabled people in institutions. Thus, the fundamental relationship between them and the residents was that of exploiters and exploited.

“Detached’ and out of touch

Miller and Gwynne agonise a lot in **A Life Apart** about their "problem*" of personal involvement as researchers. They see involvement entirely as a source of stress for themselves (and anyone else having contact with residents), and making it difficult for them to acquire a balanced and unbiased outlook as social scientists. They say, for example, "To respond to the emotional needs of the inmate, the staff member must experience an emotional involvement in the relationship; yet the greater the involvement the greater the stress"³²¹. As I shall later show, it is highly significant that they see involvement, for them and for staff, essentially as a problem in this way, and strive so hard themselves to take all possible precautions against it, so as to "acquire and maintain a balanced outlook"³²² or "regain some detachment"³²³. For this purpose, they underwent personal psychoanalysis; "relied heavily on the intervention of an uninvolved colleague to restore some semblance of balance"³²⁴; and made sure they worked concurrently on other projects. The authors paint a graphic picture of the stress and strain on them of visiting the institutions and talking to residents, and of the profound oscillations of feeling they underwent – one day overwhelmed by "pity for the plight of the disabled", and the next day seeing "the staff as victims of the insistent, selfish demands of cripples who ill-deserved the money and care that were being so generously lavished upon them"³²⁵. Miller and Gwynne were, however, consoled by the fact that the only people "concerned with the disabled population" who were not struggling with a similar ambivalence were those who were "captured by a permanent bias"³²⁶. This strange phrase, in the light of other references to staff being "captured" by residents, can only be interpreted as meaning people who support the struggles of residents for greater autonomy.

What Miller and Gwynne completely fail to recognise is that their "profound oscillations of feeling" are caused primarily by the fact that

they themselves are profoundly biased and committed against the residents' interests from the start of their research. I shall try to demonstrate this bias against us and how, as a result of it, Miller and Gwynne have conducted a project totally lacking in scientific objectivity, in spite of calling themselves "scientists". This bias is evident in their whole conception of the issues, and therefore in their chosen research methods, and in all their analyses, conclusions, and recommendations.

Their bias is embodied in the terms of reference of the Miller and Gwynne study. The terms of reference which they themselves proposed and which the Ministry of Health accepted, were in general terms, "to identify more precisely what was involved in providing residential care for incurables, and to discover possible ways through which appropriate changes could be brought about"³²⁷.

Miller and Gwynne*s interpretation of these vague guidelines is given in the words "to understand and try to tackle the problems of operating these institutions" (emphasis added), consistent with this, they claim to show that "it is possible both to arrive at more effective concepts of residential care and to recruit staff and train them to operate more successfully"³²⁸.

A Life Apart only mentions modern developments in technology and to home care facilities to proclaim their essential irrelevance to the matter in hand. There is no mention whatsoever of the Fokus housing, care and employment schemes in Europe, nor of the countless other exciting developments throughout the world in which the most severely impaired people are increasing their participation in society. Such developments prove conclusively that segregated institutions are no longer necessary, and can be replaced by much better arrangements. It follows that the basic processes at work in existing institutions can only be properly understood in the light of this key development. And above all it follows that the social oppression of residents in segregated institutions is realistically to be struggled against and eliminated.

Throughout their research, however, Miller and Gwynne restrict themselves to a narrow, blinkered approach to the issue, i.e., to try to make the institutions work a little better. They recognise the institutions in question are oppressive, and say that entering them amounts to social death: similarly, they call institutional life a "living death" and say that "institutions have inherent pathogenic characteristics" and so on³²⁹. But they want to make them work a little better.

Miller and Gwynne, the "balanced" "scientists", in restricting themselves to this narrow blinkered approach to the question of segregated institutions, are at no stage prepared to look seriously, i.e. objectively, scientifically, at the situation of physically impaired people in our society to discover whether these oppressive "social death sentences" in pathogenic (i.e. disease producing) institutions are something which must be passively accepted as inevitable, or are something which is unnecessary today and should therefore be actively struggled against. Rather than approach this question in a scientific way, Miller and Gwynne prefer to plead that, because social science is relatively medieval, the results of their research (unlike the physical sciences) have no scientific status. The results, they say, cannot be objectively verified, and therefore their principal criterion in developing their ideas about institutions is not whether they are 'true' but whether the practitioner (the person for whom the theories are designed) can make use of their new approach to enlarge his own theory of the situation he is in and extend his competence.

By pleading a lack of scientific status to their work, Miller and Gwynne avoid completely the awkward problem of its objective evaluation. An obvious point to make is that, even for the remotest scientific credibility, "external criteria" are still needed to determine whether the "practitioner" has actually enlarged his own theory and extended his competence, unless his personal feelings on this are the only test – which would be about as scientific as magic. Miller and Gwynne's formulation also abandons any attempt to establish criteria by which to determine the truth in the new theories before they have been tested in practice – it is of course precisely beforehand that it is vital to know whether a particular theory is likely to be of use. Even in their own terms, Miller and Gwynne reduce science to a set of subjective theories that cannot be verified nor evaluated. Their denial of the possibility of objectivity should be seen for what it is – a complete betrayal, not only of science as it should be, but also of physically impaired people whose needs they claim to have special expertise in investigating.

It is their bias against the residents and their betrayal of our interests that lead Miller and Gwynne to conduct a project totally lacking scientific validity. Their lame excuses about the medieval nature of their science merely erect a smokescreen around their basic error, i.e., that they nowhere question the fundamental nature of their relationship as researchers with residents. The true nature of the relationship they in

fact adopt is clearly revealed when we identify the 'practitioner*' mentioned above for whom their theories are developed. If it were the enlarged theories and competence of residents which were to be the end product of Miller and Gwynne's work and the criteria for judging the truth of Miller and Gwynne's theory, then at least the general orientation would have been the correct one. But throughout the book it is made abundantly clear that 'practitioners' are the administering staff in institutions. It is their knowledge and competence which is to be increased, while the main objects of this process do not feature except precisely as objects about whose existence someone else is to be given greater knowledge and competence. It is abundantly clear that Miller and Gwynne's bias is not in favour of Increasing the residents' control over their own lives.

Avoiding any explicit examination of the cause of the residents' "social death sentence". Miller and Gwynne have in fact adopted from the start the old medical view that it is "caused" by the severely crippled bodies of the inmates. This unexplained fundamental assumption runs right through **A Life Apart** and its acceptance is essential for their book to have even the appearance of being coherent and rational.

As early as page 4 and on page 14 they argue that, although some of the disadvantages of institutions can be mitigated, "there remains the underlying problem of irreversibility". What is irreversible in Miller and Gwynne's view is not just the impairments of residents but also the psychological and social consequences of these impairments. Clearly Miller and Gwynne maintain that the root cause of the whole problem is in our defective bodies and not in the social death sentence unnecessarily passed on us.

Throughout the rest of the book, and especially in the chapter significantly entitled Social and Psychological Consequences of Disability, again and again the authors describe the social and psychological disadvantages imposed on us as though they were natural consequences of our impairments (what they call our physical disabilities). Their view of our psychological state is summed up on page 72 as: "infirmity has psychological - even psychobiological – consequences which are often insidious and even irreversible". On the social "consequences", we are told for example on page 53 that the inability to achieve quite ordinary goals "arises out of the disability Itself". Similarly, Miller and Gwynne go on to say that the cripple has to contend,

amongst other things, with the physical, emotional, and financial dependency "that the disability imposes on his relations with others". Is it not extraordinary that supposedly balanced and unbiased social scientists can consistently be confused like this by an obvious fact, such as for example that physical impairment and low income characteristically go together in our society, into making the ridiculously naive assumption that the impairment causes the low income? This is about as sensible as assuming that women's bodies cause their low income and financial dependency in a particular society, or that black people's bodies cause them to be characteristically in low paid employment. The social disabilities of oppressed groups are not a consequence of their own physical attributes, but of forms of social organisation which discriminate against them. It is in fact those who create, maintain, and justify the discriminatory forms of organisation who in reality are the main cause of our social disabilities or death sentences.

The half-concealed assumption that our severe impairments actually cause our social problems is essential for Miller and Gwynne's attempt to justify their concentrating on the task of reconciling us to the inevitability of our social death, and for legitimising their research into how the sentence may most humanely be carried out. Miller and Gwynne say they think that in institutions the "essential task to be carried out is to help the inmates to make their transition from social death to physical death"³³⁰; and their whole research was from the start geared to assisting the staff in carrying out this task more efficiently. I do not dispute that the task as they define it is the one which is assigned to institutions in this society. But to recognise this as a present reality is not at all the same thing as accepting it as the only way things can be. As we already know, the means to overturn the death sentence and restore residents to active social life have now become available. In these circumstances, to try to reconcile residents to their "irreversible" fate is fundamentally oppressive. There is no essential difference between Miller and Gwynne's behaviour in relation to segregated institutions for people with physical impairments and the behaviour of social scientists who advise, say, on concentration camps for a racial minority, and who do not see the necessity to help the inmates to struggle for their freedom, but just limit themselves to comparing one camp with another, telling the inmates it is unrealistic to think of escape, and making recommendations for training the authorities to run the camps more efficiently.

Whatever their pretensions to giving a balanced, detached, unbiased view, the fact is that Miller and Gwynne are extremely biased against the interests of physically impaired people, and operate as agents of our oppression. Faced with any socially oppressed group, social scientists have a choice of only two alternatives: either a firm commitment to serve the interests of the oppressed group to end their oppression, or a commitment to serve the interests of the oppressors to continue their oppressive practices (which last they also do by serving their own interests). There can be no middle way.

In the first instance a scientific approach remains possible, i.e., objective reality can be looked at, and science can be placed at the service of the oppressed group to help them free themselves. In the latter instance a scientific approach is not possible, objective reality cannot be examined straight but can only be distorted. This latter approach may be obscured by talk of balance, of the medieval nature of science, and heart searching, etc, as practiced by Miller and Gwynne in **A Life Apart**.

It is commonly believed that commitment to the cause of an oppressed group means that 'reality' will be ignored or distorted, and therefore that the best scientist is the one who tries to be least involved and most detached. Nothing could be further from the truth, as **A Life Apart** illustrates. It is precisely those who try to take a detached view of oppression who cannot be objective. This emerges very clearly in relation to the notion of "parasitism". Miller and Gwynne make various references to residents as parasites, and throughout see us as essentially feeding off society not only economically but emotionally as well. However, an objective examination of the situation shows that it is not people who are segregated and demand the chance of employment who are the true parasites. The real parasites are those like Miller and Gwynne who grow fat by feeding on other people's miseries. On pages 18-19 they come out with the blatant admission that they see the institutions issue as "socially important" and "technically interesting" and as promising "both a theoretical and practical pay-off".

Parasites in search of extending their influence

It is of course necessary for Miller and Gwynne to see the institutions issue as "socially important" and "technically interesting" to justify their

claim to have an indispensably important role themselves. And it is in defence of this real parasitical interest of theirs, that would provide them with "theoretical and practical pay-offs", that they cannot face and explain objective reality, since to do this would mean recognising and abandoning their own parasitism, and that of all their fellow social scientists who approach such issues in a similar way (Erving Goffman, for example, of whom Miller and Gwynne think so highly).

On the other hand, social scientists who consciously abandon their own particular interests to serve the interests of oppressed people are freed to undertake the most careful and genuinely "disinterested" enquiry into objective reality. Oppressed groups have nothing to lose, and everything to gain, from the most precise and thorough understanding of the situation we are struggling to change. To change our oppressive reality, we cannot afford to leave out of account any significant factor in the situation: to do so necessarily means defeat and the continuation of the segregation which allows parasites like Miller and Gwynne to grow fat on our problems. Whether they are from amongst the ranks of physically impaired people ourselves, or from amongst others who seek to help our struggle forward, social scientists committed to ending our oppressive situation are the only ones who can look straight at reality - not those who are mainly on the lookout for technically interesting theoretical and practical pay-offs. A scientific approach must look at a part in relation to the whole, or institutions in relation to the society in which they exist. It must look at social forces as in a state of movement and development, not as being static; and, therefore, it must look at institutions in the context of a changing society. It must also look at the struggles of people for change in relation to the material and social changes that have taken place in the society, not as mere reactions to irreversible natural causes.

Throughout the pages of **A Life Apart** we can see how the authors' bias towards "technically interesting" work with a "theoretical and practical pay-off" conditions all their investigation, methods, and findings. The first paragraph of the Preface tells how they received from the Ministry of Health (now part of the Department of Health and Social Security) not only financial support but also advice, interest, and encouragement throughout the project. Miller and Gwynne were so grateful for their help that they voluntarily submitted a draft of their book to the department officials for comments and suggestions. It is no surprise to find that Miller and Gwynne were later commissioned by the DHSS to do research into the problems of geriatric hospital wards, and

that Miller was later to be seen leading a series of "action research" projects into health care systems of a similar type to that undertaken as part of this project.

One of the book's recommendations which highlights the interest being served by **A Life Apart** is for training courses for senior staff of institutions along the lines of some by the Tavistock Institute and Tavistock Clinic. Whether or not this recommendation ever bore fruit, at least one other form of educational or training pay-off did result. As has been noted, **A Life Apart** became one of only four set books for the Open University³³¹ course 'The Handicapped Person in the Community', which started in 1975, and for which Dr Miller was employed as an external consultant. Miller and Gwynne's "balanced" view of disability, their failure to break with the old medical model (which sees our social disadvantages as caused by our impairments), and their overriding message that staff must be found or trained to reconcile us to the continuation of our disadvantages, evidently rang the right bells for those constructing the course.

The aim of the course is given as "To enable students to improve their professional and social skills in order to assist handicapped people to achieve maximum autonomy" (Unit 1, page 5, emphasis added). A detailed analysis of the OU course is highly desirable, but it is not necessary in order to judge which part of its declared aim predominates throughout: it is sufficient to note here the uncritical use of **A Life Apart** as a key text, and the use of Miller as a course consultant who was asked to write study Unit 10 on 'Problems and Demands of Face to Face Work with People'. Clearly Miller's unit is aimed at the anxieties many professionals experience increasingly as they go about their work, whether in institutions or not. There is no doubt about the existence of this anxiety: the vital question is what is causing it, and therefore how should it be resolved? In these matters, the position taken in Miller's OU study is basically identical to that in **A Life Apart**, i.e., that the cause lies in irreversible physical characteristics of clients, and therefore cannot be resolved but only alleviated.

As I hope I have shown, Miller's orientation (and by association the OU's) is clearly not towards "assisting handicapped people to achieve maximum autonomy" as we would understand it. Rather, he totally betrayed the struggle of the handicapped people who looked to him for help in achieving this aim, and turned his efforts towards assisting the

'practitioners' – the administering staff, the "professionals" – to operate oppressive institutions more successfully.

The main training task that results from their analysis in **A Life Apart** cannot, therefore, be to help staff solve the problems that are at the root of their anxiety i.e. to struggle to eliminate the need to operate an oppressive social death sentence by working towards alternatives, but rather to alleviate the anxiety experienced by staff in order to reconcile them to 'reality' (as defined by the authors), and so in their turn to reconcile residents and others to the same 'reality'. One suggestion they put forward as a means of taking the burden of responsibility off the shoulders of staff operating these social death sentences, is to prescribe a death pill to residents entering institutions for them to administer themselves when they think the time is right.

Miller and Gwynne are in no doubt that basically these problems, like those of the residents, stem from the residents' (or clients') irreversibly defective bodies, and therefore essentially have to be accepted and lived with. However, with Miller and Gwynne's expert help the situation may be improved slightly by making various minor organisational changes, and especially by conceiving theories "to recruit staff and train them to operate more successfully". On recruitment, Miller and Gwynne suggest the development of a new kind of profession specifically to care for cripples both inside and outside institutions: the suggestion is essentially a matter of redefining "professional boundaries" and creating a profession which makes cripples its sole concern³³². Another suggestion is to use as heads of institutions mature and balanced professionals on short term loan from other fields, such as the prison service or industry, or to appoint retired businessmen, ex-service officers, and ex-colonial officials. Psychiatrists and clergymen are also thought necessary as back up resources to help heads of Homes to deal with particularly awkward problems amongst residents.

Training for control

However, what is required above all is that senior staff should receive the Tavistock kind of training. One type of "training" they advocate would be specifically aimed at helping heads of institutions to tease out the nature and implications of their task, and to find more effective ways of carrying it out³³³. What is to be "teased out", of course, is that their central

task is to help residents accept the irreversibility and inevitability of their social death sentence. There are many oppressive implications of accepting this definition of the task, and one of them is revealed in Miller and Gwynne's description of the other type of training they recommend. This is intended for people in leadership positions in all kinds of different organisations, and it is designed to "concentrate attention on the unconscious elements at work in group processes"³³⁴. By "unconscious elements" Miller and Gwynne mean the babyhood and other previous experiences which may influence the ways people behave in groups. Such unconscious mechanisms as denial of reality, splitting³³⁵, collusion³³⁶, scapegoating and projection³³⁷ are to be looked for in any situation – especially one where inmates' "infantile dependency tends to mobilise extreme and infantile strategies"³³⁸. But professionals themselves are not altogether immune from this process either, and part of what helps them to become "mature" and "balanced" like Miller and Gwynne is to be trained also to look inward at their own motivations, and backward at their own experiences as infants. This is one of the standard psychiatric methods of helping people to come to terms with intolerable situations, rather than seeking fundamental change in the situation itself. Acute anxiety and depression are commonly "treated" not just by physical assaults on people's minds (drugs, ECT³³⁹), but by concentrating attention inwards onto their own and other people's mental processes, as though they were the root of the problem. Where the training of professionals for work is concerned, especially in the case of social workers and psychiatrists, their anxieties are increasingly being treated in a similar way. By "concentrating on the unconscious processes at work", professionals are helped to become "detached" and "balanced", which helps them to intervene more effectively to control explosive situations and reconcile clients or patients to intolerable reality. This way of dealing with professional workers' anxiety succeeds only at the price of detaching them from clients: when this process goes too far, we then see the extraordinary sight of professionals ending up having to be taught how to relate to clients as though they were fellow human beings!

Miller and Gwynne's own "detached" position, which they seek so hard to propagate through training schemes that focus on unconscious elements, is revealed very clearly when they comment on examples of naked oppression. Significantly they say that any stories of oppressive behaviour by staff they were told by residents are only "alleged",

"hearsay", etc: but there were a few things they witnessed themselves which they had to accept as real. They refer to a ward consultant whom they witnessed strip a patient intent only to display her deformed legs; a unit where inmates were not allowed to eat between meals, and many had their drinking and toilet arrangements rigidly controlled; a nurse who was dismissed for having an attachment to a patient; a consultant who referred to electric wheelchairs as "expensive toys". When writing about these sorts of things in a section sub-headed 'Institutional Defences against Anxiety', Miller and Gwynne say, "some of the things we saw appalled us and although we have struggled to understand how they have come about, it is difficult to write about them without exasperation". What should be noted here is that, because they see these "appalling situations" primarily as expressions of the staff's unconscious need to 'erect institutional defences' against the anxiety produced by the inmates' deformed bodies, they actually try so hard to write about them without exasperation. "Understanding" such appalling things from this "detached" professional point of view tells us little about the possible motivations of some staff, but a great deal about the "detached" position which Miller and Gwynne seek so hard to propagate.

The function of concentrating on the unconscious elements in a situation is revealed very clearly. It is to emphasise the need for professionals like Miller and Gwynne who can help to train staff to continue to cope with the intolerable task of being the executors of the oppression of physically impaired people, and through this training alleviate the anxiety the staff experience in carrying out this role.

Conclusion (by Judy Hunt assisted by Dick Leaman)

Paul has shown us that **A Life Apart** demonstrates how the fundamental bias of these so-called social scientists, Miller and Gwynne, is against the interests of physically impaired people. The real function of their study, and of their book, has been to serve their own professional interests as parasites, making a living for themselves out of the problems of an oppressed group.

The criticism contained in Paul's article makes it clear that, when faced with professionals making recommendations on how the physically impaired should live their lives, we need to find out what interest is being

represented by those recommendations; i.e., who would benefit as a result of their implementation.

One means of finding this out is to reverse the normal situation in which others ask the questions about us, to a situation in which it is we who ask the questions, and we who thereby become informed about them. In other words, we now need to research the researchers. One method of gathering such information might be for us to face them with our own questionnaire, and Paul produced a draft of such a questionnaire some time ago, in response to an approach made to him by a social work student. Before he died, Paul indicated that he intended to publish the questionnaire as an appendix to his article, but he also expressed certain reservations on its usefulness. The validity of questionnaires in general as a means of gathering relevant information is open to question and needs to be carefully examined. The draft questionnaire published here is in no way intended to pre-empt that examination. It is put forward as no more than an example of how physically impaired people might develop, when faced by the questions of other researchers, a positive third alternative to either passive co-operation or inactive non-co-operation. Obviously, it would need to be developed and strengthened if it were to have validity for general application in acquiring information. But equally obvious are the advantages that it seeks to gain for the disabled user, by giving them some objective information about the material interest of the would-be researcher, and some subjective information of that person's own commitment in facing the reality of oppression. Any information the questionnaire can give would need careful interpretation, and it is at best a rudimentary tool to the development of which physically impaired people need to give careful consideration. But it is appended here basically as a concrete example of how we can change the relationship that is normally imposed on us by researchers – and, instead of remaining the passive respondents to prying questions, become active participants in the relationship by acquiring knowledge that will be of use to us in our struggles against all forms of segregation and for emancipation.

With the help of R. Leaman I have prepared this article for publication from a draft by Paul Hunt. I have had to write in a few amendments, reorganise some of the material for ease of understanding, and write a conclusion. I can only hope that the end result is true in content to that which Paul was himself aiming at.

Appendix

QUESTIONNAIRE

Disabled people increasingly find they are asked by researchers, reporters, film makers, etc, for personal information and opinions on disability. Until recently, my automatic response when approached with such requests was to co-operate willingly. However, it now seems to me that it is necessary to look much more closely at the kind of questions being asked, the assumptions on which they are based, and the purpose to which the information will be put. The fundamental question which we ourselves need to ask on such occasions is this: will our co-operation advance or retard the interests of disabled people as a whole? The following questions are therefore designed to help me make up my mind about whether or not I should accede to your request for information and assistance.

Confidentiality. The normal rules of confidentiality will be observed with regard to any information or opinions you give. If its use with other information for publication is ever envisaged, every care will be taken to ensure that there is no possibility of identifying you as an individual.

1. Name
2. Age
3. Occupation
4. Previous occupations
5. Parents' (or other Guardians') occupations
6. Type of school(s) attended (e.g., comprehensive, public)
7. Places of further/higher education, and subjects covered
8. Qualifications obtained
9. Any experience relevant to present project
10. Salary from employment
11. If student, grant per annum
12. If student, estimated first salary when qualified

13. Other income - please give sources
14. Estimated top salary in career path
15. Do you have any physical impairments - if so please specify?
16. How did you first become involved with disabled people?
17. Why do you think you chose the kind of work that brings you into contact with disabled people as a group?
18. Good verbal communication is impossible without agreed definitions of at least the most important terms. Throughout this questionnaire impairment is taken to mean the lack of part or all of a limb, or a defect in a limb, organ or mechanism of the body; this includes brain damage, disease or deficiency, but not "mental illness" as it is usually called. Disability is the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments, and thereby excludes them from participation in the mainstream of social activities. Please comment, and if you disagree with the definitions say why and suggest alternatives.
19. What will happen to the information gained by you (e.g., published, pigeon-holed, marked by examiner)?
20. Who will have access to the information - who is it for?
21. Who is paying the expenses?
22. Are you being paid a fee for the work (in addition to salary or grant) - if so, how much?
23. What are the exact terms of reference you are working to?
24. Please say how you think the project will help disabled people as a whole.
25. It is well known that the basic ideas which people already have when they draft questionnaires will often very largely determine both the answers they get and the subsequent selection of material for use. In phrasing your questions, what was the main thing you had in mind to find out - what idea was uppermost in your mind?
26. It is of the utmost importance that disabled people learn to distinguish between those workers on their behalf whose fundamental principles are correct, and those whose principles are incorrect. Correct principles are based on a recognition that society has now developed

the technological capacity and other means to integrate physically impaired people into the mainstream of life (that is, into employment and other related areas of life such as education, transport, and housing). It follows that the time is ripe for the elimination of disability, i.e., for full integration, and our struggles should all be directed towards this end. Commitment to this basic principle, and to others which flow from it such as the absolute necessity for the mass of disabled people to become active in tackling their own problems, is essential for professionals and others who seek to help us. Only with such a positive commitment to integration can workers on our behalf help to eliminate disability. Those who take the opposing view will instead create and entrench disability, and should be struggled against. Please comment on these statements.

27. Recently a researcher sent a Questionnaire to members of hospital management committees, and some of them were indignant at being asked for personal information. Yet researchers, social workers, etc, frequently ask personal questions of physically impaired people, and everyone concerned seems to take this for granted as a natural situation, and does not expect the roles to be reversed. The first group is characteristically active, dominant, and confident of their right to ask questions of the second group, which by contrast is characteristically passive, submissive, and careful not to question their questioners in return. In your view, why does this situation exist? And do you agree that it is itself part of what is meant by disability as defined above, and as such should be struggled against?

28. How do you feel about receiving this questionnaire?

29. Have you any suggestions for improvements to any future versions of this Questionnaire?

Section 7: 'The Future of the Union' Debate

In 1978-9, UPIAS went into its first crisis. Membership sunk to 15 (13 if non-disabled 'associate members' are excluded), and some of those remaining seriously questioned what the Union meant for the work they were doing locally, or what the point was of it carrying on. Resignations not only included newer members – who, as in all other social movement organisations, were the most likely to drop out when things became challenging – but also some of UPIAS's longest-standing and most talented organisers. While UPIAS was never a large group, and everyone understood that (at least at the beginning) only the most engaged disabled people would join, not being able to hold on to some of its most militant members threatened the whole organisation's future.

Some of the difficulties leading to this crisis are outlined in the introduction to the previous section: sometimes debates were harsh, the inaccessibility of the world left members isolated in their local campaigns, and there often wasn't the time or the confidence to do everything the Union required of its members. Perhaps more importantly, however, was the fact that UPIAS had set itself such an ambitious task that it would have been nearly miraculous for it to even have a meaningful strategy, let alone see positive results, in the first few years of its existence.

UPIAS not only wanted to build a mass movement of disabled people, but to be its political leadership at the same time. The organisation's **Aims and Policies** and the **Fundamental Principles** pamphlet had committed UPIAS to do two things: firstly, it had to help the wider population of disabled people to take control over decisions which affect their lives; secondly, it

must apply and develop its 'fundamental principles' – a political philosophy about what disability oppression is and how to fight it. In practice, there was often tension between these two elements of the Union's work. Many disabled people were getting organised amongst themselves; but because they'd realised that nobody else was going to get them the reforms that mattered to them most, not because they felt they needed a new political theory or analysis of society. As Hunt's own writings from the 1960s show, there can be a very long gap between losing faith in non-disabled reformers delivering on their promises and beginning to question the nature of society.

The result was that both the practical and the theoretical work of UPIAS were, at best, only half getting done. UPIAS as an organisation was largely isolated from the new single-impairment groups controlled by disabled people, and its members were always a small minority in local campaigns and found it difficult to influence the ideas of those they were working with. In this context, having to follow a 'line' agreed by the Union often seemed like it held members back from action, rather than guiding it. At the same time, the resignation of talented members meant that discussions on the Union's analysis of society weren't progressing. The social definition of disability, and UPIAS's claim that people with impairments were oppressed, were never considered more than the building blocks of a theory of disability. UPIAS members thought they'd got the description of disabled people's position in society right; but they knew they still needed to work out all the forces which kept them oppressed, why social barriers continued to be produced, and how to effectively fight their oppression. It was hoped that working groups and discussion circles would take these questions forward, but with a tiny membership these looked a long time in coming. This problem was particularly pressing as members were coming up against politicians, civil servants, and traditional charities in their local work; these were the gatekeepers of segregation, and sending members to negotiate with them without a full social analysis of disability seemed like sending soldiers into a war without a battleplan.

Two different approaches to these problems emerged: one proposed by Hunt, and the other by Vic Finkelstein. The debate between the two, and to a lesser extent between members falling on one side or the other, was bitter, and only really ended with Hunt's tragic death in 1979. The stakes were high: most of UPIAS's remaining members had poured seven years of their lives, not to mention their energies and hopes, into the Union, and now had to decide if it had a future. As anyone ever involved in a social movement will know, this kind of situation frays relationships between even the best of friends and the closest of comrades. We have only published Hunt's side of this debate after receiving express permission from both his and Finkelstein's surviving family, and we hope that the reader will read these pieces with careful consideration of their context.

To avoid the risk of confusion, it is worth beginning with what Hunt and Finkelstein agreed on. Neither of them, for a second, wished to get rid of either the social definition of disability or the insistence that disabled people must take control over decisions that impact them. Both members believed that, while the Union's theory and practical work were far from perfect, they were the most advanced approaches to disabled people's oppression in Britain. Any step forwards needed to protect as much of what had gone before as possible. They also shared a broad idea of **how** this work should develop. Both were Marxists, and saw the root of disabled people's oppression in capitalism's drive to make more and more profit from fewer and fewer workers; throwing whatever people it cannot profit from into poverty and dependency on charity. A theory of disability would, eventually, have to become a theory about capitalist societies; and a movement for disabled people's liberation must, in time, become part of a movement for socialism.

For Hunt, the problem was that the time was not yet right for the kind of organisation UPIAS had tried to be. There were still far too many barriers to building a mass movement able to take the disabling society head-on. Economically, disabled people were still often in poverty or vulnerable to being abused

or controlled by those that 'cared' for them (especially in institutions). This meant they could easily fall for every new 'progressive' theory dreamt up by disability professionals – who promised much, but were basically out for themselves. The fact that UPIAS had lasted as long as it had, and that it had been joined by new organisations of disabled people, proved that people would now fight for change; but this was still a small movement finding its way, and the demands UPIAS made of it had been shown to be wrong-headed. Hunt, following the Bolshevik leader Vladimir Illich Lenin, argued that you should not try to force a disciplined organisation into existence if there isn't a strong movement it can work within. Instead, you must focus on understanding how oppression works and making the case for more militant action so that, when the movement becomes strong, it has the knowledge it needs³⁴⁰.

On this argument, the only way forwards was to wind-up UPIAS. If the Union was holding back its members in their local projects, these projects wouldn't be damaged by it folding itself up; but its members could still play a role informing other disabled people in struggle. What had been preventing disabled people making progress, Hunt argued, had partly been the half-baked ideas sold to them by social reformers, which had distorted the facts of disabled people's oppression and led them down dead-end campaigns. If UPIAS members published a theoretical journal, giving disabled people a platform to work out their ideas and priorities for themselves, they could do something to rid the small movement of professional domination. This journal, unlike the disability magazines of the 1960s, should be based around clarifying exactly why and how disabled people end up oppressed, and should discuss tactics for ending that oppression. By being able to study the way society oppresses impaired people, Hunt and his supporters argued, disabled people would have a much better chance of changing that society for the better.

For Finkelstein, this simply was not how people learned how to emancipate themselves. The most important lessons about the social world are learned from trying to change it and

reflecting together on why your struggle won or lost. One of the things which had been most valuable in UPIAS, for Finkelstein, was that it had tied together political theory about disability and the actual struggles of disabled people – bringing together activists from failed campaigns to analyse what had happened and come up with a way forward. Where UPIAS had gone wrong was in letting theory and practice get away from each other – with some members not challenging the theory thoroughly enough when it caused problems in their day-to-day work, and others ignoring it entirely. Hunt's suggestion for a theoretical journal, separated from an activist group, would make this temporary mistake a permanent problem. The small but blossoming movement of disabled people would lose the one organisation able to bring various struggles together into a single discussion of oppression, and replace it with a publication which (Finkelstein feared) would involve the most educated disabled people lecturing everyone else from the side-lines.

Despite some of the less generous things Hunt says in the pieces in this section, Finkelstein didn't believe that UPIAS could just carry on as it was. UPIAS had, he argued, made significant mistakes. Members in general had been too quick to see theoretical problems as settled by the Union's policy documents and not needing any further thought, and in practical work there had been a tendency to treat each campaign as a separate fight without trying to understand what it taught the Union about the nature of a disabling society. The Union needed to open itself up to disabled people who were active elsewhere, to develop and publicise its ideas on a variety of issues, and to throw itself into more practical work to learn as much as it could from the battles disabled people were involved in around the country. All of this required more work from a membership that already felt run-down, and often faced a lot of backlash if they were too open in their radical views. In Finkelstein's defence, he had come from a liberation movement in South Africa whose members could be put in prison for handing out leaflets. He was sympathetic with any member

who felt that they could not personally cope with the demands of building a movement, but didn't believe it helped anyone to deny that this was what needed to be done.

In the next few years, history was kinder to Finkelstein's position than it was to Hunt's. UPIAS was not disbanded, and was able to take a leading role in building the Disabled People's Movement. Some people who'd resigned re-joined, along with a number of new members. UPIAS, along with other organisations of disabled people, led militant campaigns against the inclusion of Apartheid South Africa in disabled sporting events in Britain, and a segregated hostel's attempt to control a woman resident's right to have romantic relationships. UPIAS's relationship with other organisations of disabled people improved to the point that it was able to lead them into a national coalition – the British Council of Organisations of Disabled People (BCODP), which would be the most significant body in disability politics for two decades. The Union got something like its social definition accepted by both the BCODP and the Disabled People's International; the theory that had been so hard to convince disabled people of in the late-70s was, by the mid-80s, a central part of their international social movement. The social definition inspired artists, academics, and (most importantly) disabled people around the globe to think differently about how the world could be rebuilt for everyone living in it. Hunt's argument had been based on his belief that UPIAS had no clear role to play in a movement that was just being born; this belief was proved wrong.

But 1978-9 was not the last crisis of the Disabled People's Movement, nor the last time there was a conflict between what many disabled people saw as their most urgent needs and the theory developed by UPIAS. Perhaps the best compliment to Hunt's contributions below is how many of his arguments are taken up by Finkelstein nearly thirty years later in the context of larger crisis. Much of the, by then massive, Disabled People's Movement became convinced in the 1990s that rights to Independent Living and a life free from discrimination could be

guaranteed by law; and that integration could be brought about by pressuring politicians and providing enabling support services for local governments to buy instead of institutional care. Finkelstein argued the leaders of the movement had been sold a dream divorced from how capitalist societies work. In return for immediate improvements in their situation, disabled people were being forced to give up their right to define what their oppression and liberation were to the state, and their ability to launch their own social programs to the laws of the market. Like Hunt, Finkelstein then argued that disabled people needed to study the complexities of capitalist society; to develop an objective picture of social oppression before running into action, an appreciation of how capitalism was changing society before reaching for easy answers³⁴¹. Like Hunt, he argued that the movement was being captured by professional interests, who used disabled people when it suited them, and stamped on their activist networks when they were no longer useful. Again, like Hunt, he pointed to the need to get serious about what a social definition of disability tells us about the society we live in, not just the options our oppressors are willing to put on the table³⁴².

The fact that even his opponent felt the need to revisit Hunt's arguments shows how important the debate is for anyone working within a social approach to disability. While it is, at first look, a discussion about one particular group which is now long gone, the issues discussed in it come up again and again when marginalised groups try to take control over their lives. At root, the debate between Hunt and Finkelstein is about three things: how social movements take control of their own demands and strategies, rather than having rules thrust on them from outside; how marginalised people can best learn from their successes and failures to strengthen their movement; and how to turn specific battles for this or that reform into a struggle for a fairer, more equal, and more humane society overall. Those questions have not gone away – for disabled people or other oppressed groups – and we leave it to the reader to take what

lessons they can from UPIAS's early leaders attempts to think them through.

Hunt's pieces in this section are an introduction to his solution to the problems UPIAS members had identified, two responses to Finkelstein, and a final statement of the ultimate problem he believed that members needed to address – the cause of disablement in a capitalist society. Finkelstein's pieces are currently unpublished, apart from the extended quotes from them in the articles here.

The Future of our Union³⁴³ (1978)

In order to decide the best way forward at the proposed conference³⁴⁴, it seems to me important that we try to discuss as fully as possible the Union's experience from its beginnings in 1972 to the present time, in the context of the developing situation in 'disability' and in society as a whole. We should I think re-examine and, if necessary, change our ideas and our forms of activity and organisation to ensure that, with presently available resources, we are making the maximum contribution we can to the struggles of disabled people as a whole. We must try to fit our forms of activity and organisation to the tasks to be done rather than trying to fit the tasks into the present framework we have created. I hope these notes will give some impetus to the discussion we surely need to have in view of the present circumstances of our organisation.

In going back over the Circulars and other Union documents and weighing up what has happened so far, it seems to me indisputable that the process of discussion, mainly through the Internal Circulars, which led up to the Policy Conference in October 1974, was much more important than anything else ever produced in the disability field in this country. The **Policy Statement** itself was, and remains, streets ahead of other disability organisations' efforts in its clear and principled approach to our struggle. It is particularly strong in the way it is based firmly on the modern development of the technological and other means for our integration, thus sketching the beginnings of a full explanation of our developing struggles as a group; and also in its insistence on the necessity for all physically impaired people to become increasingly active in the struggle. None of our opponents have been able to show that our approach is in general incorrect. For example, when we applied the **Policy Statement** in the long correspondence with the Cheshire Foundation, they had no sensible answer to make. And when the **Policy** was again applied and developed in the case of the Disability Alliance

there was a similar result, despite the greater sophistication of the opposition.

Those of us who have argued the Union's position with friends and other contacts have I think found a similar inability to show us where the **Policy** is basically wrong, even when people clearly don't like it. This is not to say that the **Policy** doesn't have weaknesses and obscurities, and doesn't need a lot of developing. I am just making the point here that no-one has yet been able to offer us a better analysis of our situation or a clearer notion of the way towards ending our oppression.

Publishing and promoting the **Policy Statement** and **Alliance booklet** are by no means the only achievements to be entered in the plus side of the Union's five-year balance sheet, but they seem to me the most important, and for the sake of brevity I will not list all the others here. However, re-reading the Circulars (a task which I hope all members will undertake) shows that we have a lot to be proud of in view of the great difficulties we have been working under.

The most obvious minuses in our balance sheet are such things as our loss of membership and general inability to enthuse other disabled people with Union ideas, the lack of much tangible effect (e.g. no Fokus-type units built at our prompting); the small amount of money and poor facilities at the Union's disposal; our inability to find allies amongst other 'self-help' disability groups, our failure to do so many of the things we set ourselves in the **Policy Statement** – most significantly, we have not set up even one of the promised study groups nor published any of the proposed 'Open Newsletters' and so on. But although these things are disappointing and disturbing, they are not I think reliable indicators that anything is really wrong with our organisation. It could be just that quick results were never to be expected, that the struggle against oppression is necessarily hard, that we must put in more effort and look to the future when the other organisations in disability are shown to be inadequate, or even positively opposed, to the real changes we need.

However, I think there is another, more important, indicator that there is something seriously wrong with our Union. The principal indicator, in my view, is not so much our 'practical' failure but rather our failure to raise our theoretical level substantially in the years since our founding conference. This failure has two main aspects which are closely interrelated. One is the failure of members in general to move substantially towards an independent understanding, application, and

development of Union principles as set out in the **Policy Statement** (and Alliance Commentary). And the other aspect is the failure of our organisation to make substantial progress in developing the necessary theory or comprehensive explanation of disability to guide the struggle for our emancipation. To put it another way, most members have not been able to grasp the essence of the **Policy**, and such theoretical development as there has been has not dealt with the heart of the matter – the essential nature of the society which disabled us.

Eighteen months ago, Vic Finkelstein pointed to these problems in his notes explaining why he would not be General Secretary (C. 20, November '76)³⁴⁵. Firstly, he emphasised the need for members to make the Internal Circulars

“a living means of extending and developing, through constructive criticism, the policy of the Union. Arguing about the Union’s **Policy Document** is a process through which it can become possible for those less theoretically developed to extend themselves so as to contribute to the organised struggles of disabled people. The central role of the **Policy** document lies in its ability to act as a living guide to action.... By making the **Policy** (that is its ideas) our own, we can be freed to act independently and at the same time in accord with all those members in the Union who have already agreed to the **Policy Document**”

Vic went on to state in very strong terms the need for members to become increasingly active in understanding, developing, and acting on the **Policy** – “or else there is no future for the Union in the struggles of disabled people”. Unfortunately, in the eighteen months since Vic made these statements, the level of contributions to the Circular and of independent activity by members has declined even further. There are still no study groups, and no contributions to the External Newsletter – and many members are not just less active but have left altogether. This is not to say that past and present members have done nothing at all, but to make the point that the Union’s **Policy** is not really being used in the “living, guiding way” Vic called for. Instead, it has been allowed to “rot and lose its core role as the source of action and guidance for all members” (all emphases are Vic’s).

In the same article, written just after he had completed his work on the **Alliance Commentary**, Vic said:

“our analysis is far from adequate. At best we have laid down the direction for further development of an adequate, correct theory of disability. This task cannot wait”. Vic said he would be concentrating on “pushing our understanding forward” by becoming “more involved in the basic issues that face us in our oppression

This basic task of developing and disseminating an adequate theory (or comprehensive explanation) of our oppression is something the Union itself has not engaged in at all since the Alliance work was completed. Yet all our struggles as a Union, and all the continuing struggles of disabled people as a group, show more and more clearly that the key task at the moment is precisely the development of a comprehensive explanation of the central issues in disability for the use of disabled people as a whole. Without a grasp of such an explanation, and of the means for developing it further, disabled people will remain confused and disunited, and oppressed by the ‘experts’ (Morris, Agerholm, Goldsmith, Townsend, Miller and Gwynne, etc) with their false theories and leadership. Our practical work itself will suffer unless its development is related to an increasingly adequate explanation of disability – which can only be achieved as part of an increasingly adequate explanation of the economic, political, and ideological forces at work in society as a whole, since they largely determine what happens in our small area.

By the standard suggested here (the necessity for substantial theoretical development at all levels of the organisation) the Union is failing to do the vital work required by the struggle. The most important beginnings of an explanation of disability, partly expressed in the Union’s **Policy Statement**, have not taken root amongst disabled people either in or out of the Union, and any subsequent analysis and theoretical development has been the work of very few people with most members passive and silent – and is anyway “far from adequate”.

What are the reasons for this failure to build substantially on the Union’s excellent start? Firstly, what about the failings of members – of those of us who have taken a leading part, and of others who have been rather less active. Personally, I am conscious of certain weaknesses on my part which have affected the way the Union has gone, and am prepared to discuss these with members. However, I do not think we can look principally to personal failings for an explanation for the decline of

the Union; even in the period after the Policy Conference, when some of us were putting in more effort and enthusiasm, the internal life of the Union did not develop really constructively. Another possible reasons for our decline could be the severe difficulties we have faced such as immobility, geographical isolation, shortage of cash, lack of energy etc. If members had been able to meet together regularly, use the phone more, circulate material more efficiently, and so on, our problems would certainly have been eased and such things as study groups might have been set up, for example. But although our practical problems of this kind have undoubtedly contributed towards preventing the Union from flourishing, I think they cannot be considered decisive. Members of other oppressed groups have overcome great obstacles in organising against their oppression – in fact the existence of such obstacles is part of oppression. Also, both in Britain and abroad groups of disabled people managed to get organised over a period of time – even if often at a lower level than we have been aiming at.

In getting at the main reasons for our decline as an active organisation it is useful to note something else which occurs in Vic's Circular 20 article. He refers several times to members agreeing with the **Policy Statement**, but also uses interchangeably the term we actually put on the membership form – i.e., accept. In fact, all members have, by joining, accepted the **Policy Statement** (and the **Alliance Commentary** since it became Policy by default) but very few have actually agreed with it. Our Union has been formally, 'officially', a national Union of people committed to a commonly worked-out detailed policy. But in reality we have only been united, only been a real Union, on a much more limited basis. We have agreed on two points, basically: 1) that the way forward towards the solution of our problems as physically impaired people lies in the general direction of social integration rather than segregation (though we have usually differed when coming to the application of this principle to any particular issue); and 2) that the other disability organisations are inadequate – undemocratic and unresponsive to disabled people, and too narrow in function and outlook (though again our unity at this general level has not always survived the test of practical application).

On the very many occasions we have seen that a large majority of members who accepted the **Policy** found themselves disagreeing with vital parts of it and with the way in which it was applied by the Union leadership. And when they tried to be active themselves, they found they

were open to criticism as not being true to Union principles. Now, as I have said, I'm still convinced that the Union approach is nearer to the truth of things than anything else in disability in Britain. So how is it then that with this helpful policy to guide them, the majority of members have not come to agree with its basic principles but have instead increasingly drifted away? The short answer is that for each of us the **Policy Statement** and **Alliance Commentary** are necessarily looked at, interpreted, in the light of underlying theories and assumptions about our situation which have not been discussed at all fully amongst ourselves. In the Union there have been, and still are, major underlying differences of outlook on disability – which are in turn only part of major differences in our positions on social and political issues in general. For example, the big argument we had about using the term 'oppression' to characterise our situation was not only an argument about whether or not the term was accurate or 'too strong' etc; it was also an argument about whether our proposed organisation should situate itself within the working class tradition of militant struggle for emancipation through change in the economic and political structure of society as a whole, or should take up pressure group politics for a bigger slice of the cake of the kind practised by DIG.

In the Union, on a whole range of issues the existence of two 'wings' with very different outlooks has been discernible throughout our existence. On the one hand there are those few of us who are convinced that the struggle for integration necessarily involves not only the fight for immediate improvements, but also a mass struggle for radical changes in the way society as a whole is organised. On the other hand, the majority of members have always considered that the struggle for integration can, and should, be treated as distinct from wider social and political issues, with progress best being made by concentrating on achieving practical improvements here and now. The Union has gone in for too much abstract theorising which will get us nowhere and which puts off potential supporters who think we are too antagonistic and 'left-wing'. (This 'split' is of course a tendency within the group, and does not mean that individuals belong completely to one wing or the other).

As is well known, the policy of the Union has been developed, formulated, and applied principally by those of us who are convinced of the necessity for radical social change if integration for all is to become a reality. The Union's policies therefore contain a commitment to such changes as: the phasing out of all segregated institutions, schools,

workshops etc; the active participation of all physically impaired people in social struggles; the abolition of the competitive labour market (implied on page 1 of the **Policy Statement**); and “employment and full social participation made accessible to all people, including those with physical impairments” (page 15 of the **Alliance Commentary**). Most members, while accepting the policy documents, have not agreed with radical conclusions such as these, and have therefore found great difficulty in using the policies independently in the liberating way that was hoped for. Naturally there is a strong inclination to take from the policies only what can be assimilated into a member’s own underlying ideas and beliefs on disability and other social issues. And this has led to most members finding themselves frequently at odds with the basic perspective of the Union and the section of its leadership which has mainly been responsible for policy formulation and application.

This lack of underlying ideological unity amongst us is a fact which we need to acknowledge, in my view, as a precondition for further advance. We should also acknowledge the fact that the Union has become increasingly isolated from the mass of disabled people: at present, policies such as ours do not appeal to any section we have been in touch with. There is no sign that this will cease to be the case even if we promote Union policies more energetically, change our tactics or the groups we try to reach, etc. Like the majority of people in Britain at the moment, disabled people are not receptive to ideas of militant struggle for radical change – despite their often-desperate circumstances and the undeniable fact that the basic means for change have been developed. Indeed, this is even more the case now than when the Union was started, as the other self-help groups seem to have been drawn into effectively supporting the status quo. For those of us who are convinced that integration for all is now a real possibility, an analysis is evidently required of the forces in society which are holding it back and which prevent physically impaired people from joining and supporting an organisation such as our Union.

The exact time when a radical mass movement of physically impaired people in Britain becomes possible (as it certainly will) is not something we can predict; my present view is that it depends largely on very major economic, political, and ideological changes taking place in society as a whole. What we can do, however, is to prepare for and hasten that day by developing a leadership forged in the struggle for the new ideas and

new forms of practice required for integration. For the reasons I have attempted to begin sketching in these notes, I do not think the Union is now a suitable organisational form for that preparation. The Union policy functions at the moment mainly in a negative sense. It inhibits members from becoming active in the Union and from taking initiatives as members in relation to non-members – consequently we have each been doing our own thing outside the Union without reference to the organisation. And the policy is now holding back the work and discussion essential to the development of a comprehensive explanation of disability.

I think we should therefore dissolve the Union, issuing a statement giving a brief explanation, and saying that we are continuing the struggle in a new form of organisation. This I suggest should be an organisation primarily for the purpose of publishing a journal. This new journal should be based on the main points on which we have general agreement amongst ourselves at the moment – that is, it should be pro-integration and democratically run, with freedom of information and discussion on how to achieve integration. Through such a journal it should be possible to extend (though in a different way) the invaluable discussion we have had in the Union to involve wider sections of disabled people and friends. We could also highlight particularly important examples of good and bad practice from Britain and abroad, analyse relevant developments etc. While keeping in touch through our work on the journal, ‘members’ would be able to pursue their own activities without having to conform to a detailed unified policy or being committed to support the views expressed by others. In this way there would be scope for helping each other with the various projects we are undertaking, as well as promoting them through the journal. Opportunity would also be there, for those of us who see the primary need as being for the development of theory, to publish our ideas and have them discussed, try to popularise them and so on. A variety of study/discussion/action groups associated with the journal might be stimulated as we progress. I suggest that our general aim should be to help to create a pro-integration movement at a higher level than we have at present as a pre-condition for the formation of a new Union which builds on the foundations laid by UPIAS.

This article is already longer than I intended, so I won’t go further into the idea of a journal-type organisation for the moment. Much better if

others will put forward their ideas about the present situation and where we should go from here.

Reply to Vic Finkelstein³⁴⁶ (1979)

There are four particularly curious features of Vic's article circulated just before our Conference in October³⁴⁷.

- (1) Although he seems to acknowledge that there is a crisis in the Union, that it is failing to meet the requirements of the struggle, nowhere in his article does Vic address himself seriously to the fundamental question of why it is not working.

After two years in the wilderness “pushing our understanding forward”³⁴⁸ Vic can offer no explanation for the Union's crisis – but just says “there is, however, an urgent need to find ways of making the Union work”! What else have we been trying to do but this for the past four years? Most of us have been putting our energy mainly into what calls the “nitty gritty” of organisational questions and day-to-day contacts, of trying to make the Union work. It is precisely this practical work which has been accompanied not just by a loss of members, but by the failure of remaining members to become increasingly active in understanding, applying, and developing the policy. It is this failure which forces on us the question of what is wrong with the Union, and in fact poses the issue in terms of inadequate theory rather than practice. This is so because the theory as developed so far in the Union has not provided us with the tools for explaining the present crisis and therefore knowing what new guidelines for action **are** appropriate. This is confirmed by Vic's own two-year search for answers outside the Union³⁴⁹

Vic has in the past taught us that, in order to deal effectively with a problem, the cause must first be identified. But what is most remarkable is that in this present crisis, despite his claim to have developed the theory outside the Union, he has so far offered us nothing in the way of analysis. Instead, he asks us to follow him in his compulsion to find ways

of making the existing Union work, without any serious consideration of the lessons to be learned from our years of experience in trying to do just that.

- (2) The second curious feature of Vic's article, which is mostly a polemic against my views, is that in all its six pages he makes no mention at all of the main weakness in my position! The chief criticism to be made of my Circular 24 article is this: if I think the present Union is inadequate for the key task of the "development of a comprehensive explanation of the central issues in disability for the use of disabled people as a whole", then I should put forward proposals for strengthening the Union to enable it to do this vital work.

Instead, my Circular 24 article is at fault in trying to skip this difficult stage of the struggle, assuming that there is no point in trying to develop the Union in the direction considered necessary. I can now see that only if such an attempt were to prove impossible would it be right to consider alternatives such as a journal-type organisation. This has become clear to me mainly through the discussion at the Conference at Cressy Fields, and through [Member G]'s article in Circular 26, which rightly begins to focus on key inadequacies in the **Policy Statement**³⁵⁰.

If it is true that Vic's opposition to the dissolution proposals, like that of most members, intuitively recognised the requirement for further struggle to make the Union policy adequate to the tasks we face, then to this extent his reaction to the crisis has a positive element. But it really is strange that Vic fails to point out this requirement in all his lengthy polemic. In fact, [Member G] develops my original article in his later contribution and focusses much more clearly on the central weakness in the **Policy Statement** (and **Alliance Document**). This weakness is its ambivalence on the central question of the cause of disability – i.e. the fundamental cause of the "misdirection" of the already achieved capacity to bring about our integration.

The failure to make the Union work urgently poses the necessity for us as a group to clarify this basic issue, so that we know much more clearly just what we are up against in the struggle. As Vic said as long ago as Circular 3:

"I believe that a major task, concomitant with the struggle for practical changes we wish to make to society, is to clarify

issues. We cannot, after all, effectively struggle against something if we remain unsure as to exactly what we feel is wrong”³⁵¹

Unfortunately, in this present crisis, Vic has abandoned what he has taught us for so long. Instead of seeking a real explanation for the Union’s crisis, which involves a struggle in the Union for a clearer explanation of the fundamental cause of disability, Vic now says the need is “not for more theory but for practical work”. Just when we need to re-examine and clarify both the position of disabled people in society, and the Union’s experience of struggle, to get at the cause of the crisis, Vic asserts (he certainly doesn’t argue it) that the only thing needed is more “practical” work of essentially the same kind as has preceded the present crisis. This head-in-the-sand, empiricist approach is a sad reversal of Vic’s earlier insistence on clarifying the fundamental cause of any situation we wish to change.

Vic is not only failing to practice what he has preached from the earliest days of the Union; his approach to the present crisis is also diametrically opposed to an essential principle of the **Policy Statement**, which is expressed under the heading Guidelines for Action. This is where we commit ourselves to

“learn from the practical struggles which take place. So, an essential part of the Union’s task is to develop increasingly clear guidelines for further action. We will do this by careful discussion about what we and other disabled people are doing, and about the real nature of the problems we face at a particular time”

Vic is ignoring this passage in his present approach – yet this is the one section of the **Policy** which gives the most relevant guidance in our present situation. There is, at the moment, no sign of Vic attempting to “develop increasingly clear guidelines for action.... by careful discussion”. Instead, Vic offers us only an off-target polemic against other people’s views, which serves to obscure rather than clarify the real nature of the problems we face – even to the point of missing the chief weakness in his main opponent’s position.

- (3) Vic derides my view that the principal indicator that there is something seriously wrong with the Union is:

”not so much our ‘practical’ failure but rather our failure to raise our theoretical level substantially... This failure has two main aspects which are closely interrelated. One is the failure of members in general to move substantially towards an independent understanding, application and development of Union principles as set out in the **Policy Statement** and Alliance Commentary). And the other aspect is the failure of our organisation to make substantial progress in developing the necessary theory or comprehensive explanation of disability to guide the struggle for our emancipation”

These statements are fully in line with what Vic said in Circular 20, as the quotations on page two of my article show. But Vic is now falling back on a quite different criterion for judging the success or failure of the Union which deserves our careful attention.

On page five of his recent article (3/10/78) he asks “When is a bird a lame duck?” and proceeds to ‘answer’ his question by reference to Galileo(!) and by telling us what we know already – that a theory only becomes generally accepted when it is seen to work in practice. This echoes the **Policy Statement** which says: “The Union will succeed only when it helps to achieve real benefits and improved conditions for disabled people”. But this vague statement, though true, is of no more help to us than Vic’s latest formulation. The crucial question for us now is what is meant by a theory for emancipation (or an organisation based on it) ‘working’ in the first years of struggle to get it accepted.

Even if the Union had, for instance, been instrumental in getting some Fokus-type units established, and substantially improved conditions in some institutions, such valuable achievements would not in themselves prove that the Union was meeting the requirements of the struggle – just as our failure to bring about these changes so far does not prove we are on the wrong track either. The same applies to the questions of numbers of members, funds, influence in ‘high’ places, etc. These are not the decisive criteria since in each case objective factors are involved which are largely or wholly outside our control. The fact that technological developments now make our integration possible does not mean that the specific economic and political conditions in Britain are also conducive to the quick growth and success of an organisation such as ours which rightly seeks to eliminate disability, as we say in the Alliance Commentary

The Union has not yet begun to take account of the particular economic and political institutions which hold sway at present over the population as a whole in Britain: but it is clear at least that as long as these institutions, and their accompanying practices and ideologies, remain dominant they strongly favour, not the growth and success of the Union, but the growth and success of Alf Morris and the Disability Alliance. So, in judging whether or not our organisation is working, we need to recognise not just that in the last analysis history is decisively on our side, but also the magnitude of the forces at present arrayed against us and which we have to find ways of overcoming in alliance with other oppressed groups. No matter how adequate its basic theory and strategy, and no matter how correctly its struggles are undertaken, no organisation which seeks radical social change to eliminate oppression can be judged a success or failure in terms of short-term 'practical results'. The demand which can, however, be made of any such organisation is that it is clear about the fundamental cause of the situation it seeks to change, and that this clear perspective is applied and developed in all its activities.

- (4) The fourth curious feature of Vic's polemical article is that it is full of distortions of my views. I do not propose to demonstrate every one of these distortions in detail, though I will of course do so if Vic requires it. A comparison of Vic's article with what I actually wrote can be made any time to show that the bird he shoots at so wildly is in fact a clay pigeon of his own making.

Two examples will suffice to demonstrate this. On page two of his article Vic quotes me as saying that no-one has been able to "show us where the **Policy** is basically wrong... This is not to say that the **Policy** doesn't have weaknesses and obscurities, and doesn't need a lot of developing". A few sentences later Vic paraphrases this view of mine as: "We have a policy that cannot be faulted". Similarly, he goes on to interpret my statement: "None of our opponents have been able to show that our approach is in general incorrect" as meaning that there is "nothing wrong" with the Union's approach or policy.

It must surely be clear enough to anyone with an open mind that saying our opponents have not been able to show us where the Union policy is basically wrong is not at all the same thing as saying it "cannot be faulted". To say that we are streets ahead of the Disability Alliance, the Cheshire Foundation, etc, is no indication at all that our policies are

necessarily adequate to the requirements of the struggle. In fact, the first passage from my article, which Vic himself quotes, makes it very plain that I think the Union policy does have weaknesses and obscurities, and does need “a lot of developing”! All in all, Vic’s misrepresentation of my views here is really very strange, especially coming as it does from someone who has had the full benefit of academic studies and well knows the basic rule of good polemics – make sure you understand and answer your opponent’s real views and not ones you have invented for him.

In the course of his article Vic also tries to prove that the purpose of the proposed new journal was to “educate” disabled people while keeping them “in the side-lines”. He ignores the fact that my proposal said: “I think it is essential that...as many physically impaired people and friends as possible should become associated with the project as co-controller and contributors, and not just as subscribers”. This is hardly keeping physically impaired people in the side-lines! As far as my priority, the development of a comprehensive explanation of disability, is concerned, I proposed that this work should be published, discussed, and popularised in the new journal. It is important to note that I was suggesting that those of us who were attempting to develop an explanation of disability should publish our views and the reasoning behind them for discussion with other disabled people through the journal, whereas Vic’s two-years of theoretical work outside the Union cannot even be discussed with Union members, let alone a journal for disabled people.

Still on the subject of “educating” disabled people; at our recent Conference Vic agreed that the **Policy Statement** is unclear about the cause of disability, and that this vagueness is perpetuated in the Alliance Commentary. Yet he is quite happy to see this vague organisation of ours as an adequate vehicle for educating disabled people. On page four of his article Vic has this formulation:

“the Union takes a leading role – it does not rely or organise around what we would expect under conditions of oppression, the confused and often backward thinking of disabled people, but it leads the thinking by concentrating on changes to the real world which we have to help disabled people into changing their thinking so that it more and more corresponds with objective (outward) reality”.

Since the Union is, on Vic's own admission, confused about the fundamental cause of disability (i.e., about the most important part of "objective (outward) reality"), how can it be relied on to educate and lead other disabled people and help them into "changing their thinking"? The "education" problem is really Vic's, not mine.

To summarise now, we have seen how Vic's article is "deadly silent"³⁵² on the fundamental questions of the cause of the Union's crisis and the real cause of disability. We have noted how he falls back on a vague truism when supposed to be answering the question of the criteria for judging whether or not our organisation is working. We have also seen how Vic's polemic distorts my position (and [Member G]'s) while managing to miss its main weakness. And we have noted how Vic's uncritical support for the Union's present policy leads him into the very errors he accuses me of so forcefully.

On the evidence just of this single article of his, it is not possible to explain with certainty the cause of Vic's strange behaviour in this crisis in the Union. This much is clear, however: when analysing an individual's or a group's position in the struggle the basic question to be decided is whether or not their approach is basically in the real, common interests of disabled people as a whole. Judging by his article it is evident that Vic's present position is opposed to those interests (as was mine and [Member G]'s in trying to evade the requirement to pursue the struggle for clarity about the cause of disability in the Union, in the first instance). The struggle for increasing clarity and accuracy is the hallmark of any approach which is in the real interests of an oppressed group; obscurity and distortion can only serve the interests of our oppressors. We must hope that Vic's recent article is only a temporary lapse, and that he will now take up again the struggle for clarity which he so rightly used to urge on us.

I intend now to circulate as soon as possible an article in which I will develop my views about the key inadequacies in our Union's present position, and attempt to show how these can be remedied so that in our future struggles we would be guided by and united around a much clearer view of the fundamental cause of disability.

Forward from Basics – 2nd Reply to Vic Finkelstein³⁵³ (1979)

In his latest contribution to our argument³⁵⁴, Vic ignores all the criticisms I made of his current position in my C27 article³⁵⁵. I showed there how Vic is at the moment abandoning the high standards he once set us in the Union. Since the points I made were important ones, I hope Vic will let us have his reply in the near future.

Despite the fact that he has not yet tried to answer one of my criticisms, Vic says that I have evaded his own criticism of me on what he calls “the basic issues” – i.e., that of method. As is implied in my C27 reply to him, the reason I did not tackle the issue of method directly was because I consider that the most important thing is to focus primarily on the concrete issues of why the Union has declined and what we should do about it. However, I agree that the question of method is also a vital one and am very willing to discuss it in more detail as Vic asks. In the course of the discussion, it is possible to see further weaknesses in Vic’s position similar to those I uncovered in C27.

Vic’s chief criticism is that I started my search for the main reason for the Union’s decline with “subjective” considerations, by “looking into the minds of our members”, rather than by looking outward at the “objective real world”. It is necessary first to distinguish the method of presentation of an argument from the method of analysis itself – a distinction Vic fails to make in his comments. In both the examples he gives I did start the presentation of the argument by referring to the Circulars and other Union documents (what he calls the mind of the Union). I referred to his confusion over whether most members had agreed (fully) with the policies or had just accepted them, as a way of presenting, a lead into, my argument that objectively there had been a major underlying disagreement between two main wings throughout the history of the

Union. Obviously, Vic's confusion on this point proves nothing about the existence of this disagreement, and my Circular 24 article makes no attempt to use it as a proof of anything.

There is a similar point to be made about my reference to the Circulars and other Union documents at the start of my C24 article. Vic argues that I start my analysis by looking inwards "into the 'mind of the Union', its Circulars and documents", and says that throughout my paper I argue in this way "from theory (or the thinking and views of our members) to explain reality (or what has happened in the Union)".

It is instructive to look at what I actually said in my article: "in going back over the Circulars and other Union documents and weighing up what has happened so far..." (emphasis added). By omitting the words underlined, Vic obscures the fact that I was attempting precisely to weigh up "what has happened in the Union" or "reality". The best way of reminding ourselves of that reality is to go back over the Circulars etc. In fact, my article went straight on to summarise many of the achievements and failures, or pluses and minuses, in four out of five of the paragraphs on page 1!

It is strange that Vic accuses me of starting from theory to explain what has happened in the Union, when all the evidence shows that I started precisely with an attempt to sum up what has happened in the Union, and in our dealings with the rest of the "real world" – and also made it clear that I started from the fact that the technological and other means for integration have been developed. It is the contradiction between the fact of this development, and the fact that the Union has nonetheless failed to flourish as we were once convinced it would, which my analysis starts with. My explanation (or short answer) for this state of affairs is that there has been a basic underlying disagreement within the Union. Objectively, as we can remind ourselves by re-reading the Circulars etc, most members "have found great difficulty in using the policies independently in the liberating way that was hoped for", but have instead "found themselves at odds with the basic perspective of the Union and the section of its leadership which has mainly been responsible for policy formulation and application". This long history of conflict occurred in the "real world". I go on to say that for those of us who are convinced of the real possibility of integration for all now, an analysis is evidently required of the forces in society which are holding it back and which prevent physically impaired people from joining and supporting an organisation

such as our Union. Again, the reference here is obviously to the real world and the need to develop our ideas about it.

In fact, throughout my article, it is plain that the difference of view in the Union has been about how to achieve our emancipation in the world, which my short answer recognises has been only part of major differences in our positions on social and political realities in general. What I was chiefly concerned to establish was that there has objectively been this major underlying disagreement. As long as we proceed on the false assumption that we all have fundamentally the same outlook, we will continue to find ourselves at odds even over simple practical matters – without understanding why and therefore without being able to see a way forward. All Vic has to say on this vital issue is his dismissive “It is patently obvious that if members do not in fact agree (...) with Union policies then the Union won’t work”. – Yes, this is patently obvious, but the real question is whether most members have in fact agreed or not. On this Vic is now again “deadly silent”, which contrasts strangely with what his attitude used to be.

In Circular 26 Vic says: “the case for integration is not principally made by noting what goes on in the minds of people but by what goes on in society as a whole, which people then think about”³⁵⁶. It’s true that the case for integration is principally made by showing that the means for it have been developed, as we did, for example, in the Cheshire Home correspondence³⁵⁷. But this is not what the present argument is about: the case for integration is not at all in dispute. What is in dispute is whether the existing Union is the best possible organisation for pursuing the struggle for integration at this time; in particular, whether it takes sufficient account of “what goes on in society as a whole” – most importantly the vested economic and political interests which work against our integration.

The other main problem with Vic’s formulation on method just quoted is the phrases: “...what goes on in society as a whole, which people then think about”. Things are not in reality quite that neat. Vic’s formulation is a mechanical one, suggesting an absolute, one-way process in which things go on in society and people then think about them passively, whereas in fact the relationship is a dialectical one³⁵⁸. The ideas people already have about what is going on also partly determine not only what is perceived “out there” but also what does actually happen. Although ideas always originate in what is happening or has happened “out there”,

they are also an active force which shapes the world in part. The point scarcely needs labouring – but Vic himself gives an example in his [article **Union of the Physically Impaired**], where he says that [Members H & I] should have made it clear in [a media interview] that their “practical work reflected the policies of the Union”. In other words, that Union thinking about what goes on in society has led [them] to change what goes on in society.

One final point. Vic says that “stagnation” rather than “decline is more apt to characterise the Union’s situation which we are trying to remedy. To diagnose the process that has already taken place over the last few years as “stagnation” hardly seems adequate in view of the progressive falling off of activity and membership. However, it is also interesting to note Vic’s claim that his “perfectly correct position” is “rational and consistent with the position [he has] always maintained in the Union”. With regard to consistency, I would refer him back to what he said when he was seeing things rather more clearly.

“No organisation remains static, and if I am correct then the Union will take a position one way or another (...) whether we consciously decide to do so or not. For my part, I am not willing to mindlessly remain in an organisation which sinks into ineffectualness through the lack of struggle by its members to move forward”³⁵⁹

Now he describes the situation in the ensuing two and a half years as stagnation. I think he was right before and wrong now – but either way it is difficult to see where consistency comes in.

Some weeks ago, Vic told me he was going to propose that another meeting be arranged. I support this suggestion, and hope if others agree [Member H] will be able to make the necessary arrangements in the near future. I should like to propose that the main items on the agenda should be (1) the cause of the Union’s crisis and the cause of disability and (2) the proposals put forward by Vic in Circular 28 for leaflets, an education pack, Newsletter etc³⁶⁰.

The Cause of Disability and our Union³⁶¹ (1979)

In Circular 24³⁶² I attempted to draw up a balance sheet of the Union's activities to date, and argued that despite our achievements and the relative strength of our policy documents there is something seriously wrong with our organisation. I said that the problem is not so much our 'practical' failure but rather our failure to raise our theoretical level substantially in the years since our founding Conference. One aspect of this failure is that members in general have not moved

“substantially towards an independent understanding, application and development of Union principles... And the other (closely interrelated) aspect is the failure of our organisation to make substantial progress in developing the necessary theory or comprehensive explanation of disability to guide the struggle for our emancipation”

I went on to say that I considered that the

“key task at the moment is precisely the development of a comprehensive explanation of the issues in disability for the use of disabled people as a whole. Without a grasp of such an explanation and of the means for developing it further, disabled people will remain confused and disunited, and oppressed by the 'experts'... with their false theories and leadership”

I maintained that the Union had shown itself inadequate for this key task, because members were ideologically disunited on the basic perspective of the Union, and this had bedevilled our work together. The basic division was between those of us who see the need for radical change in society as a whole if full integration is to become a reality, and the majority of members who have shared the current view of most disabled people that the struggle for integration can and should be treated as distinct from the wider social and political issues.

My C24 article ended with a proposal that the Union should be dissolved and suggested that we continue the struggle through a looser journal-type organisation which recognised our present differences while still allowing us to work together in various ways. Subsequently, at our October meeting [Member G] and I withdrew the proposal, and in C27³⁶³, I said I thought we had been mistaken in trying to jump over the requirement to attempt to change Union policy if we considered the Union inadequate for the tasks facing us. I ended this second article by saying I would “develop my views about the key inadequacies in the Union’s present position, and attempt to show how these can be remedied that in our future struggles we would be guided by and united around a much clearer view of the fundamental cause of disability”. This present article is intended to fulfil that commitment.

In C26 [Member G] identified for us the central weakness in the **Policy Statement** (and **Alliance Commentary**) as its ambivalence on the question of the cause of disability - that is, the fundamental cause of the ‘misdirection’ of the already achieved capacity to facilitate our integration. This reference to ‘misdirection’ occurs in the first paragraph of the **Policy Statement**, headed Disability and Segregation, which says that Britain has enormous technology and know-how which could help overcome disability – except that the way this capacity is mis-directed (into such things as sophisticated weapons) means that physically impaired people are still unnecessarily barred from full participation in society. This statement (which I have paraphrased here) is undoubtedly true; and, as I have said before, the Union’s relative clarity on this point is one of the things which makes its policy streets ahead of those of other disability organisations in Britain. However, the fundamental question which is still begged here is why this enormous capacity is mis-directed. In other words, what is the cause of the disability of physically impaired people – what is the main obstacle in the way of our integration?

This same key question is left unposed and unanswered throughout the whole of the sketched analysis which makes up the first part of the **Policy Statement**. It is true that there are one or two points where a possible answer is hinted at, and I will come to these in a moment. But, firstly, it is important to stress the fact that while the **Policy Statement** is strong in its insistence on the huge gap between the historically developed potential for our integration and the grim reality of our continued segregation, it is very weak on the crucial explanation of why

this gap continues and even gets wider. Our own years of struggle in the Union, and the struggles of so many other organisations and individuals over a long period, continually pose anew the fundamental question of why all this effort comes to so little in the end. Why is it that the oppressive system adjusts and grows and seems to incorporate, isolate, or stamp on even the most promising movements for change? Since we know that the basic means to full integration have been developed already, an explanation of why they are not systematically applied to facilitate our integration is essential if we are to direct our struggles into the right channels.

The place in the **Policy Statement** where we come nearest to offering an explanation of this is in the second paragraph of the section headed Recent Advances. This is where we say:

“This society is based on the necessity for people to compete in the labour market in order to earn a living. To the employer of labour, the physically impaired are not usually as good a buy as the non-impaired. We therefore end up at or near the bottom of this society as an oppressed group”

In the next paragraph there are a couple of ironic references to the “needs” of the economy and to “when business starts to boom once more”, which together with the ‘tone’ of this section of the document reinforces the impression that the Union may have some sort of vaguely anti-capitalist orientation. Within this context, and at a superficial reading, the statements about physically impaired people’s relation to employment just quoted might be taken to imply the necessity to abolish the labour market, as I suggested in Circular 24³⁶⁴.

There are in fact major problems with these important statements, as they are not just inadequate but positively misleading, and they perpetuate all the old views about our situation. But for present purposes it is sufficient just to note that whatever might be inferred here about the cause of disability, there is no attempt to grapple directly with this central issue in the whole of the **Policy Statement**. [Member G]’s question about whether the ‘misdirection’ of resources is accidental or fundamental is not posed, let alone answered.

There is a similar absence in our most recent policy document, the **Alliance Commentary**. In it we claim to be dealing with the “fundamental principles of disability”, and we say that unlike the ‘experts’

we have turned to question the real cause of disability. We go on to say that there is a single cause within the organisation of society which causes our disability: and that the need to make a full analysis of society is most pressing as this leads to the very essence of disability (see for example pages 11, 14 and 15). But this is as far as we go in dealing with the cause of disability – just pointing in the general direction of a defective social organisation. This still begs the same really vital questions as are avoided in the **Policy Statement**: why is our society organised to exclude us and why is the struggle to change this organisation – or rather dis-organisation – so hard even though the means for change have basically been developed?

It is important to note, however, that both the **Policy Statement** and the **Alliance Commentary** – despite some inconsistencies – were evidently written by people who think they have a good idea what the basic cause of disability is, although this is not made explicit. (This ambiguity is, as I argued in Circular 24, the source of many of the difficulties other members have had in trying to apply the policies in practice). The implied cause comes nearest to the surface in the commitment made in the **Alliance Commentary** to “struggle for changes to the organisation of society **so** that employment and full social participation are made accessible to all people, including those with physical impairments” (page 15).

To advocate struggle for the changes suggested here would be utopian unless the real potential for “employment and full social participation for all” exists already. And, in fact, this potential has been developed. The creation of the means to integrate physically impaired people has just been part of a whole process whereby tremendous means for human development have been produced, and for the first time in history the real possibility of employment and full social participation for all has been reached. But standing in the way of realising this full potential is the very system of social organisation which has created it. Developing in its turn from earlier kinds of social organisation, our present form (capitalism) is based on competition and the profit motive. It is not hard to see that production for profit, with its necessary accompaniment of a competitive labour market, is not compatible with employment and full social participation for everyone. To stay in business, the capitalists must in the end sell their products at a competitive price and make a profit. In order to do this, they must be able to hire and fire workers as necessary: the changes that have taken place since the early days of “free” small-scale

capitalism (unionisation; monopolies; state ownership; subsidies; etc) only modify this to a limited extent. A pool of unemployed labour is an essential requirement in all 'normal' times, to be taken on when demand picks up or new businesses start, and laid off again when there is a recession or as particular industries decline. Also intrinsic to the capitalist process is the need for employers to continually use more and more sophisticated technology to keep up with or overtake their competitors in efficiency or productivity per worker – and of course many workers become redundant as they are replaced by machines. These developments in technology have played a big part in making physically impaired people increasingly capable of participation in the mainstream. Yet we still provide a sizeable proportion of the more or less permanently unemployed and are likely to continue to do so for as long as we have to compete against able-bodied people for a diminishing number of jobs.

What the capitalist form of organisation has produced, however, is the means for replacing it with a form of organisation which will enable us all to share increasingly in co-operative control of employment and the rest of life. There have been enormous achievements in exploitation of natural resources, in developing agricultural and industrial productivity through technology and large-scale working, etc. Taken together with the workers' consequent high level of knowledge, variety of skills, and capacity for organisation, this means that potentially control of society can now pass out of the hands of the minority who at present monopolise the benefits of the great transformation that has taken place, and into the hands of the majority. The foundation of society can be planned production for use rather than chaotic production for profit as it is now. Just as we have established in the Union, by looking outward into the real world, that potentially there need be no unemployment amongst physically impaired people, so it can be established in a similar manner that there need be no unemployment for anyone else either. All socially necessary work (which includes the kind of help we need) could be shared out amongst everyone, with further advances in technology used to shorten the standard working day rather than throwing people out of work altogether. In fact, the new potential that physically impaired people controlling our own lives has occurred, and could only occur, in the context of related developments for the majority of people.

We therefore have a basic common interest with many others in struggling for the necessary changes to a form of social organisation which excludes them from full participation as well as us – though of

course we experience certain specific kinds of discrimination which other groups do not. In the struggle for improvements, potential solutions to our problems are continually being constructed in the present society. But in all struggles for systematic, fundamental change we necessarily come up against those who in [Member G]'s words "control and benefit most from our present society"³⁶⁵. A relatively small minority defend and perpetuate a form of social organisation which has outlived its time, and in so doing they oppress us all by denying us the shared control of our lives which is now possible. This capitalist form of social organisation which they defend is in the last analysis the cause of disability for us as well as for most people. This is so not just because it is outmoded, wasteful and irrational, but also because it is in the nature of the capitalist relation to exploit workers by robbing them of control over the full fruits of their work in common, and allowing bigger and bigger surpluses to accumulate in the hands of the few. This process of disabling exploitation is the basic mechanism through which this society functions, and exploitative social relations of an analogous kind are the norm in every area of life where they are not consciously overturned. This is evident enough in the 'disability world', with its parasitical social scientists like Townsend and Miller and Gwynne, for example, or the mushrooming bureaucracy of RADAR³⁶⁶ and Motability³⁶⁷. They are all "cultivating the field of disability", to quote Goldsmith's revealing description of his own activity³⁶⁸.

So, our struggle is not just that of an oppressed minority group in a basically healthy, non-oppressive society, as is assumed by all pressure group politics for a bigger slice of the national cake for this or that unfortunate minority. We live in a fundamentally oppressive society, and our integration requires a radical transformation in the way the whole society is organised. The cause of disability lies at the very heart of the "contemporary social organisation which takes no or little account of people who have physical impairments and this excludes them from participation in the mainstream of social activities"³⁶⁹. It can at first be depressing even to suspect that the root of our problems lies so deep and that such fundamental change is required for our integration into the mainstream of society. Nevertheless, if we claim as a Union to be the leading group in disability in this country, we need to decide consciously whether or not our campaign for the 'right to work' and full social participation can succeed as long as society is organised on capitalist lines.

On the answer given to this question depends our whole perspective and way of working for practical change. For example, where do we look for alliances in the struggle for change in our oppressive conditions of life? Do we look for mutual help to the managers of our oppressive society, to those who run things at present? Or do we look to other oppressed groups – amongst which the industrial working class is central. (One small practical example could be the movements at Lucas Aerospace, T E Parsons, Vickers etc, where workers struggling to avoid redundancies have come up with detailed plans for applying their skills to making socially useful things such as kidney machines instead of weapons, etc³⁷⁰). Do we place our hopes for change in disability on getting a bigger slice of present or future national cake, like DIG, the Disability Alliance and virtually every group you can think of including the major political parties? Or do we see that, while it is essential to struggle for better conditions and against the encroachments on what has been gained already, the distribution of wealth (such as the aids we need) is determined under capitalism basically by the process of production for profit which operates by laws which are essentially opposed to the efforts of those who seek 'equitable' income schemes and the like. As long as production is for profit rather than for use, not only are the wrong products or the wrong quantities produced, characteristically, but the necessary resources for purchasing aids and so on are accumulated in the hands of a few and denied the majority of us.

I don't propose to continue developing these ideas now, as the main point about the cause of disability has at least been introduced. Nor am I suggesting any policy or organisational changes or practical applications at the moment. The important thing it seems to me is that the basic issue of the cause of disability should be discussed in the Circular and at a forthcoming meeting as freely and openly as possible.

Commentary

All notes in square brackets are Hunt's footnotes/endnotes in the original documents.

20 Editor's Introduction

For historical accounts of life in chronic wards, see Maggie Davis and Ken Davis's [To and from Grove Road](#) published by TBR in 2019, and Tony Baldwinson's [We are Bloody Angry](#), also from TBR in 2022 (a heavily revised third edition is pending publication at the time of writing). Both books combine accounts of the older chronic wards – where older and younger people lived together – and the 'Young Chronic Sick Units' which only housed people under 65

21 In fact, it always had been: as far back as the 18th century, the government had paid the lion's share of the bill for asylums and workhouses – although all day-to-day decisions were made by charities and local officials.

22 For a history of how the word 'disability' was used in British law, government, and civil society after the war, see Jameel Hampton's 2013 article 'Discovering Disability: the General Classes of Disabled People and the Classic Welfare State, 1948-1964' in **The Historian** (Vol: 75; Issue: 1 – pp. 69-94)

23 See pages 31-33 of Judy Hunt's [No Limits: The Disabled People's Movement, a Radical History](#), published by TBR in 2019

24 From the 1958 Cheshire Foundation **Mission Statement**

25 See **The Le Court Patients' Welfare Fund** in this volume

26 See David Marshall's of the Carnegie Trust's speech, reproduced in 'Opening Day' in the first issue of the **Cheshire Smile** in 1954 (Vol: 1; Issue: 1 – pp 4-5)

27 For an overview of the early conflicts in Le Court, see pages 43-47 of Judy Hunt's **No Limits**

28 See the Ministry of Health's **Annual Report: 1959**, quoted on page 81 of Hampton's 'Discovering Disability....'

29 These anxieties were expressed repeatedly by the Cheshire Foundation's managers and leaders at their 1963 Annual Conference, reported in the Autumn 1963 issue of **The Cheshire Smile** (Vol: 9; Issue 3. Pages 9-22)

30 See the July 20th entry in **The Journal of Paul Hunt: 1962**, published by TBR in 2021

31 See the entry for June 24th in **The Journal of Paul Hunt: 1962**

32 See the June 20th entry in **The Journal of Paul Hunt: 1962**

33 See Leonard Cheshire's article 'Summing up' in the Winter 1964 issue of **The Cheshire Smile** (Vol: 10; Issue 4 – pp. 21-22)

34 See **Young Chronic Sick Don't Want Units** in this volume.

35 See **Patients or People** and **Comment – Winter 1967** in this volume

36 I am grateful to Judy Hunt for allowing me to quote this private letter

37 For an overview of disabled people in the welfare state and politicians' views of disability, see chapters three and four of Jameel Hampton's 2016 book **Disability and the Welfare State in Britain: Changes in Perception and Policy 1948-79**, published by Policy Press in Bristol

38 See Gareth Millwards 2015 article 'Social Security Policy and the Early Disability Movement—Expertise, Disability, and the Government, 1965–77' in the journal **Twentieth Century British History** (Vol: 26; Issue: 2 - pp. 274–297)

39 See **Justice for the Disabled** and **Justice, Not Charity** in this volume

40 See DIG's 1965 press release **Notes on DIG** – attached to their first newsletter in **The Judy and Paul Hunt Collection** at Manchester Central Library

41 I am grateful to Judy Hunt for this insight

42 See pages 69-71 of Judy Hunt's **No Limits** and Paul Hunt's **Policy Paper to the 1973 Conference of the Disablement Income Group** in this volume

43 See, for example, Agerholm's speech to the Cheshire Foundation's 1964 conference, published as 'Helping the Disabled to Live to Capacity' in the Winter 1964 issue of **The Cheshire Smile** (Vol 10: Issue 4 – pp. 14-20)

44 See, for example, Goldsmith's article 'The Disabled: A Mistaken Policy' in the September 1976 issue of **The Royal Institute of British Architects' Journal** (pp. 105-107)

45 These arguments were put forward in Goffman's books **Asylums: Essays on the Social Situation of Mental Patients and Other Inmates**, published in 1961 by Anchor Books, New York, and **Stigma: Notes on the Management of Spoilt Identity**, published in 1963 by Penguin Books in New York.

46 **A Life Apart: A Pilot Study of Residential Institutions for the Physically Handicapped and the Young Chronic Sick** was published by Tavistock Publications in London in 1972

47 See **Parasite People** in this volume

48 See Agerholm's 1975 article 'Handicaps and the Handicapped: A Nomenclature and Classification of Intrinsic Handicaps' in the **Royal Society for Health** journal (Vol: 1975; Issue: 1 – pp. 3-10)

49 See **Settling Accounts with the Parasite People** in this volume

50 First published by Geoffrey Chapman in London. A new edition is forthcoming through TBR.

51 While a deeply offensive term now, 'Spastic' was a common word for someone with Cerebral Palsy during the '60s and '70s

52 A remarkable series of articles in the April and May 1965 issues of the society's magazine **Spastics News** shows how deep frictions were in the organisation. An anonymous worker, an anonymous manager, and a disabled resident – Rosemary Dawson Shepherd – very publicly accused each other of making the Society's services dreadful places to live and work. By the end of the year, the Society's senior case worker, a Miss M Richards, argued that the Society should not open any new Hostels or day-centres until the disputes were resolved. See Richard's 'Indications for Residential Care' in the December 1965 issue of **Spastics News** (pages 4-5)

53 For more information on the National Campaign, see Tony Baldwinson's **We are Bloody Angry**

54 There has been a recent debate about whether the Act was a total failure or a partial success (encouraging some councils to act differently, even if they didn't have to). Even the scholars most sympathetic to Morris and the Act, however, agree that in many parts of Britain nothing changed at all for disabled people. For discussion of the Act's drafting and passage into law, see Tony Baldwinson's 2020 pamphlet [Alf Morris MP and the Campaigning by Disabled People that Led to the 1970 CSDP Act](#), chapter five of Hampton's **Disability and the Welfare State in Britain**, and Millward's 'Social Security Policy and the Early Disability Movement'

55 See, for example, UPIAS member Dick Leaman's account of Ealing Borough Council's failure to consult disabled people on a new segregated hostel: 'A Union of the Physically Impaired Fighting Against Segregation' in Issue 1 of [Disability Challenge](#) (pages 17-26)

56 See **Comment – Autumn 1968** in this volume

57 See NFB Chairman Fred Reid's speech to its annual conference in 1973 – published as a pamphlet and stored in **The Judy and Paul Hunt Collection** at Manchester Central Library.

58 See **Comment – Autumn 1968** and **Priorities of Change** in this volume

59 See **Notes on the Nature of Our Organisation** and **Reply to [Member D]** in this volume

60 See **The Need for Discussion and Study** in this volume

61 For Finkelstein's presentation of this argument to all UPIAS members, see his [Are We Oppressed?](#), originally written in 1974, and published by TBR in 2018

62 See **Correspondence with Sir Christopher Foxley-Norris** and **Active Social Participation for the Handicapped** in this volume

63 See : Mike Oliver's 1992 article 'Changing the Social Relations of Research Production?' in **Disability, Handicap & Society**, (Vol 7: Number 2. pp. 101-114 – quoted text is from page 112)

64 See chapter 2 of Ann Shearer's 1981 book **Disability: Whose Handicap?** published by Blackwell in Oxford.

65 See Goodley's 2012 essay 'Jacques Lacan + Paul Hunt = Psychoanalytic Disability Studies' in the book **Disability and Social Theory: New Developments and Directions** edited by Goodley, Davis, and Hughes, and published by Palgrave Macmillan in London. The quotes are from pages 178 and 192.

66 See William's 2001 essay 'Theorizing Disability' in **Handbook of Disability Studies**; edited by Albrecht, Seelman, and Bury, and published by Sage Publications in London (pp. 123-144)

Section 1: Early Writings

67 **The Journal of Paul Hunt 1962** (Page 23)

68 **The Journal of Paul Hunt 1962** (Page 12)

69 **The Journal of Paul Hunt 1962** (Page 13)

70

71 First published in the **Cheshire Smile** (Volume 4: Issue 2) in June 1958

72 The Home's Warden at this time was Alan Finch

73 First published in the Autumn 1960 edition of **The Cheshire Smile** (Vol. 6; Issue 3). Hunt is here reviewing two books published in 1959: Dr Russell Barton's **Institutional Neurosis** (London: John Wright & Sons), and John Vaizey's **Scenes from Institutional Life** (London: Faber & Faber). Both books are currently out of print

74 Dr. Russell Barton qualified as a psychiatrist in 1958. He had been one of 96 medical students to visit the Nazi's Belsen concentration camp in Northern Germany in 1945 – shortly after it was liberated by the Soviet Red Army. Barton believed that there were similarities between ways that prisoners were controlled by the Nazis and how mentally distressed people were treated in British hospitals – including strict control of daily routines and a stifling of prisoners' or patients' individuality. Barton wrote his views in an article for **Purnell's History of the Second World War** – a popular monthly magazine. His article was incredibly controversial. The book that Hunt is reviewing here was written before what is now called 'the Barton-Belsen controversy', but contains many points Barton would return to later. For more on Barton's life and work, see Claire Hilton's 2018 article 'Dr Russell Barton, Belsen concentration camp and 1960s psychiatric hospitals in England: the controversy' in the journal **Contemporary British History** (Vol: 32; Issue 3. Pages 307-335)

75 John Vaizey – later made Baron Vaizey of Greenwich by Prime Minister Harold Wilson in 1976 – was a British economist and economic historian. Vaizey lectured at Cambridge, Oxford, and Brunel Universities, and wrote a number of books about the economics of education, the history of British industry, and the relationship between trade unions, employers, and governments. **Scenes from Institutional Life** is his only book about disability or residential institutions.

76 Hunt is here quoting a review of *Institutional Neurosis* by M. Wilson in *The Almoner* (June 1960)

77 This piece was first published in the Spring 1961 issue of **The Cheshire Smile** (Vol: 7; Issue: 1) as a review of **Mr. Lyward's Answer** by Michael Burn (London: Hamish Hamilton, 1956). This book is currently out of print, but an abridged version of its first edition is [available online](#) from the Finchden Manor website:

78 Michael “Micky” Burn (1912-2010) was a British journalist, poet and playwright. Originally sympathetic to Nazism as a student, Burn became convinced in the mid-1930s that Hitler’s policies were creating misery for poor people in Germany. Burn volunteered to join the British army at the outbreak of the Second World War, and was involved in attacks on German military bases in Norway and France. He was captured by the German army and spent the rest of the war in a Prisoner of War camp in northern Germany - where he became a Marxist and converted to Catholicism after conversations with fellow prisoners. **Mr Lyward’s Answer** was one of three non-fiction books he published, and the only one to deal with residential institutions.

79 George Aubrey Lyward (1894-1973) was the founder of the Finchden Manor community, and seems to have been the only person who made decisions about how the community was run, its rules, or what was taught to the children there. Lyward originally trained as an Anglican Priest, before getting a job as a Schoolmaster in Clapham in South London. Following a mental health crisis, Lyward bought a farmhouse near Guildables in Kent, and in 1931 began using it to teach (in his words) the type of ‘boys who were sent away’ from other schools ‘for delinquency’ (from **Mr Lywards’ Answer**, Online Edition. Page 40). He later moved the school to Tenterden

80 Mrs. Lyward is never named in either Michael Burn’s book or in the Memorial Speech for Lyward written by former pupil John Prickett (published on the Finchden Manor website). In both, she is referred to only as ‘Mr. Lyward’s wife’.

81 At this point, it was usual for volunteers and workers at Cheshire Homes to live in (or very near) the Homes. See, for example, page 57 of **The Private Journal of Paul Hunt**, published by TBR in 2022.

82 It is unclear who Mr. Bruce is. It may be a typing error, with the quote actually from Michael Burn, but the following sentence does not appear in the online edition of **Mr Lyward’s Answer**. Alternatively, the quote may come from another reviewer in a different publication.

83 Hunt’s review first appeared in the Winter 1961 issue of **The Cheshire Smile** (Vol: 7; Issue: 4). Wills’ book was published in 1960 by Goliancz publishing house in London. It is currently out of print

84 David Wills (1903-1981) was involved in a number of therapeutic communities for young people who'd been kicked out of school or were at risk of being sent to prison. Along with other members of the Quaker community – a Protestant religious movement that promotes pacifism and egalitarianism – Wills helped run communes for young offenders, and specialist hostels for children evacuated from cities during the Second World War. He was appointed Warden of Bodenham shortly after the war ended, and retired in 1961.

85 **Living Proof** was a film produced by the Le Court Film Unit about daily life in the Le Court Cheshire Home in Hampshire. A copy of the film has been digitised and can be found [online](#). The story of the film makers – themselves all Le Court residents – is the subject of Tony Baldwinson's 2019 study [Le Court Film Unit: an Award-winning Disabled People's Film Crew 1958-1969](#) (Manchester, TBR Imprint) Hunt's review was published in the Summer 1962 issue of **The Cheshire Smile** (Vol: 8; Issue 2).

86

Ian Curtis produced a handful of TV documentaries for the BBC in the late 1950s and early 1960s. He went on to make training videos for television producers and editors. In a later interview for the film [People Who Challenge](#), Brian Line from the Film Unit describes Curtis getting involved in the film as 'sheer luck'. Curtis happened to have moved to the village of Liss, near Le Court, had somehow found out that **Living Proof** was being made at the Home, and offered his services.

87

Pathfinder was a one-off, hour long documentary broadcast on BBC television in 1960 (although the exact date and time of the broadcast is unclear)

88

Mai Zetterling (1925-1994) was an actress and film director, most famous for her roles in films **Torment** and **Music in Darkness**, directed by famous Swedish director Ingmar Bergman, and for playing the leading part in a film adaptation of **The Witches** by Roald Dahl (directed by Nicholar Roeg). At the time she became president of the Film Unit, she was an incredibly famous and controversial figure: the first film she directed, **War Games** (1962), criticised Britain and the USA's ownership of nuclear weapons, and her follow up, **Loving Couples**, was banned from Cannes Film Festival because it contained explicit sex scenes. We have no evidence that Zetterling was directly involved in producing or directing any of the films made by the Le Court Film Unit, but the Unit was able to use her name to

fundraise and get access to filming equipment they otherwise could not afford. See pages 7-8 of Tony Baldwinson's **Le Court Film Unit**

89

90

The two book reviews that make up this piece were published as a single article in the Winter 1962 edition of **The Cheshire Smile** (Vol: 8; Issue 4)

91

Two Lives was published in 1962 by Hutchinson's publishing house in London. It is currently out of print. x

92

Peter Marshall (1939-1972) was a British author. After **Two Lives**, he went on to publish two novels – **The Raging Moon** and **Excluded from the Cemetery** – before dying at the age of 33. His novel **The Raging Moon** was adapted into a film – directed by Brian Forbes and starring Malcolm McDowell and Nanette Newman. At the time this review was published, Marshall lived at the Heatherley Cheshire Home in Sussex

93

So Briefly My Son was also published by Hutchinson's in London in 1962. Like **Two Lives**, it is currently out of print. Very little information is available about the rest of Neville's life and work – it does not appear that she published any other books or articles.

94

This review was published in the Summer 1963 edition of **The Cheshire Smile** (Vol: 9; Issue 2)..

95

Father Hubert McEvoy published several short compilations of prayers on different subjects across the 1940s, '50s, and '60s. **In Time of Sickness**, his collection of Catholic meditations on illness, was published in 1962 by the religious publishing house Burns and Oates in London. It is currently out of print.

96

These are all sacraments within the Roman Catholic Church's calendar of prayers and services.

97

Section 2: The Role of the Residents Debate

The Journal of Paul Hunt 1962 (Page 60)

98

See, for example, the 1962 letters between Paul Hunt and Peter Wade of the Residents' Welfare Committee with Leonard Cheshire and Sir Earnest Gowers of the Foundation's Trustees, held in the **Judy and Paul Hunt Collection** at Archives+ in Manchester.

99

For first-hand accounts of the Foundation's decision see 'Annual conference 1963' in **The Cheshire Smile** (Volume: 9; Issue:3) (Pages 9-22)

100

From Leonard Cheshire's 'The role of the residents' **The Cheshire Smile** (Volume: 9; Issue: 3) (Page 27)

101

Vade in Pacem ('Go in peace'); the name of a Catholic commune founded by Cheshire in 1946 on the original Le Court site. The commune soon fell into financial difficulties and was disbanded in 1947.

102

From Cheshire's 'The role of the residents' in Vol:9; Issue 2 of **The Cheshire Smile** (pages 11-13)

103

For example, Barbara Beasley's 'Current controversy' in **The Cheshire Smile** (Volume: 9; Issue:4) (Pages 46-47); Brian Line's 'Co-partnership' on pages 47-48 of the same issue; and Peter Hanson's 'Our public image' from Volume 10; Issue 2 of the **Smile** (Page 19), as well as Hunt's articles below.

104

These include letters and articles from residents Cornwall, Bristol, Kent, and Southampton

105

These included L.J. Tirebuck, who worked as an administrator for the Foundation, a Mr Geddes who was headmaster of a school, and a professional soldier named Mr Scott..

106

Leonard Cheshire 'Summing up' in **The Cheshire Smile** (Volume: 10; Issue: 4) (Page 21)

107

See Leonard Cheshire's letter to Frank Spath, dated 17th February 1965, in **The Judy and Paul Hunt Collection** at Manchester Central Library.

108

The Journal of Paul Hunt 1962 (page 5)

109

This letter was published along with the earliest responses to Cheshire's call for discussion of the "Role of the Residents" in the Spring 1964 edition of **The Cheshire Smile** (Vol: 10; Issue: 1).

110

New Horizons was founded by a group of disabled people living in a state hospital in New Britain, Connecticut, USA in 1955, who aimed to collectively run and manage independent living communities for disabled people. They first took action by negotiating control over a ward in the hospital, where the disabled patients were allowed to set care routines, organise the social activities of the ward, and end the use of large dormitories.

Later, the group bought a patch of land in Connecticut with the aim of a self-managed community for disabled people. Very little information is available about **New Horizons** apart from short articles published in **The Cheshire Smile**: Joan Herman's 'Self management – productive living – co-operative endeavour' (Vol: 11; Issue: 4. Page 30), and 'Why New Horizons?' (Vol: 12; Issue 2. Pages 20-21). See also Paul Hunt's **New Horizons in the U.S.A** in this volume.

111

This letter was published in the third set of contributions to the 'Role of the Residents' debate in the Autumn 1964 issue of **The Cheshire Smile** (Vol: 10; Issue 3).

112

Not only Leonard Cheshire, but also Frank Spath (editor of **The Cheshire Smile**) had provided funds to **New Horizons** to help them buy land for their new community. See the editorial note on page 20 of the Summer 1966 issue of **The Cheshire Smile** (Vol: 12; Issue 2)

113

This piece was published in the 10th Anniversary issue of **The Cheshire Smile** in Winter 1964 (Vol: 10; Issue 4). Unlike previous pieces, this article was published alongside a short editorial note by Frank Spath, reminding readers that 'the opinions put forward by an individual contributor are not necessarily those of the Foundation'

114

The phrase Hunt attributes to Beasley is not present in any of her published articles in **The Cheshire Smile**. It's likely that Hunt is quoting a private conversation.

115

Barbara Beasley was a resident at Le Court, the secretary of the Le Court Film Unit, and a prolific writer in the **Cheshire Smile** – writing its women's page throughout the early '60s, as well as various other articles. Like Hunt, she was deeply critical of Homes becoming more hierarchical and medicalised, and argued that attempts to control residents' behaviour and activities basically amounted to treating them like children. Her own early contribution to the Role of the residents' debate largely set the tone for the letters to the **Smile** afterwards. See her 'Current Controversy' in the winter 1963 issue of the **Cheshire Smile** (Vol: 9; Issue: 4 – pp. 47-8)

116

The Ryder-Cheshire Mission (later renamed the Ryder-Cheshire Foundation) was a charity set up jointly by Leonard Cheshire and his wife Sue Ryder (who had set up residential communities for terminally ill ex-soldiers and holocaust survivors shortly after the end of the Second World War). The Ryder-Cheshire Mission was mostly active abroad, and ran residential homes in India, Poland, and Palestine, amongst other places.

117

This letter was probably written in late January or early February 1965, but was never published in **The Cheshire Smile**. As Hunt's letter was a response to Leonard Cheshire very publicly announcing that the debate was over, Frank Spath (editor of **The Cheshire Smile** at the time) sent him a copy and asked his view as to whether it should be made public. Not surprisingly, Cheshire was not keen on the magazine publishing another piece suggesting a view contrary to his own, nor on the debate continuing after he'd announced its end. Cheshire claimed that 'an open letter is not really called for' and that, instead, Hunt should 'write (..) to me personally' to try and sort out the issues quietly. At this point, Hunt didn't feel he had much option except to drop the letter, and instead ask Cheshire to try and reform the rules that allowed residents to be evicted by Management Committees – where Cheshire seemed to be more willing to compromise. See: Leonard Cheshire's 'Letter to Frank Spath' (17th February 1965); Paul Hunt's 'Letter to Leonard Cheshire' (23rd February 1965); Leonard Cheshire's 'Letter to Paul Hunt' (26th February 1965); and Paul Hunt's 'Letter to Leonard Cheshire' (1st March 1965) in the **Judy and Paul Hunt Collection** at Archives+ in Manchester.

118

See Leonard Cheshire's article 'Summing Up' in the Winter 1964 edition of **The Cheshire Smile** (Vol: 10; Issue: 4. Page. 21)

119

'G.C.' stands for Group Captain – Cheshire's rank in the Royal Air Force when he retired. Referring to him by his military rank was a show of respect by the Homes' residents.

120

Margaret 'Greta' Agerholm was the rehabilitation consultant at the Inner London Education Authority (the body which managed London's schools) and a trustee of the Cheshire Foundation. Agerholm, perhaps even more than other professionals involved in the Foundation, is an example of a radical critic of mainstream "care" services who later became their conservative defender. In the 1960s and early '70s, Agerholm argued that disabled people's views should be given priority over doctors' in the design of rehabilitation programmes, and that the problems facing disabled people were mostly social, and should not be approached as medical issues. By the end of the decade, however, Agerholm was

constructing physical 'classifications' of 'handicaps' – dividing up everything from incontinence to spinal injuries into their most-and-least severe medical forms – which she claimed governments and health services should base their disability policies on. For an overview of Agerholm's early work see Vic Finkelstein's 1975 article 'Phase 2: Discovering the person in 'disability and rehabilitation' in **The Magic Carpet** (Vol: 27; Issue: 1). For Agerholm's later position see her 1975 article 'Handicaps and the handicapped: a nomenclature and classification of intrinsic handicaps' in **The Royal Society of Health Journal** (Vol: 95: Issue 1)

121

See Agerholm's **Helping the Disabled Live to Capacity** in **Cheshire Smile** (Vol. 10; Issue. 4) (Pages. 14-20)

Section 3: Institutions

122

In the early and mid-60s, journalists and academics (most notably Peter Townsend and Barbara Robb) were writing regularly about the loneliness, dehamnisation and abuse of older people in hospitals and local authority care homes.

123

For the amount of money spent on new segregated institutions in the late '60s and early '70s, see the Office of Health Economics' report **Physical Impairment: Social Handicap** (1977) (Page 13)

124

Robert Moroney **The Family and the State – Considerations for Social Policy** (published by Longmans, London in 1976) (Page. 147)

125

Erving Goffman **Asylums** (Page 37)

126

Goffman **Asylums** (Pages 363-366)

127

Goffman **Asylums** (Page 29)

128

A shortened version of this article was published in **The Guardian** newspaper on the 10th of March 1965 and is republished on pages 43-46 of Tony Baldwinson's **We Are Bloody Angry**. The version here comes from Hunt's longer final draft, which is held in the **Judy and Paul Hunt Collection** in Manchester.

129

Workhouses were the buildings used to house poor and unemployed people under the Victorian Poor Laws. While a small number of disabled people were allowed to receive 'outdoor relief' - money from their local church or city officials –, many could only get help with housing or food if they agreed to live in a building that would also be their workplace. Inmates were not free to leave when they pleased, and alcohol, singing and games were often banned. The food was usually dreadful, and inmates were not paid for their work.

130

It's likely that this survey refers to the Williams Committee – set up by the government to investigate the staffing needs of long-stay hospital and residential homes. See Hunt's **Comment – Winter 1967** below for more information on the committee's report.

131

There is no full copy of this memorandum kept in Hunt's papers, and it is unclear who else worked with him on it.

132

This is the second draft of preparatory notes for pamphlet sent to Tony Smythe – the General Secretary of The National Council for Civil Liberties (now called Liberty) in February 1967. Hunt had sent the first draft several months previously, but after an initial expression of interest by Smythe, contact dried up. After this draft was sent, the Council sent a member of its staff to Le Court to meet Hunt, but there is no evidence that any pamphlet on residents' rights was produced.

133

The Poor Laws (enacted first in 1601, and then amended in 1834) dictated who had a right to receive benefits or charity from local churches and government. Initially a way of staving off starvation for poor workers – particularly in the countryside – by the Victorian era the Laws were mainly used to force rural workers to move to the cities where there was more work. Under these Laws, the majority of people could only receive help with food and lodgings if they moved into one of the ‘workhouses’ that Hunt mentions elsewhere. As they were forced into backbreaking and meaningless work in the workhouses, many people avoided asking for help at all costs – no matter how poor they became.

134

The Mental Health Act (1959) was a law which defined when doctors could detain and treat a mentally distressed person without their permission – a power which has never been extended to disabled people as a whole. The Act was concerned with deinstitutionalisation – trying to move many people who doctors called ‘mentally ill’ from segregated settings to the community. The Act abolished the difference between Lunatic Asylums and Hospitals, meaning that doctors had to justify keeping people in hospital by ‘proving’ that their illness could not be treated elsewhere, and that the patient was a risk to themselves or other people if they did not receive treatment. The Act also abolished the law that allowed doctors to lock up people for being ‘moral imbeciles’ – a term often applied to people with learning difficulties and women who had had sex outside of marriage

135

Hunt is probably referring here to a controversy started by an anonymous whistleblower writing in **The Lancet** (the journal of the British Medical Association). This article, and a follow-up investigation by the journalist CH Rolph in the magazine **New Society**, revealed that many hospitals for older people “stripped” their patients on admission – taking away any item which staff believed they could use to harm themselves. Campaigners, including Rolph, argued that older people were unlikely to try and hurt themselves at all if long-stay hospitals were not such desperate and depressing places, and set up a reform group called Action for the Elderly in Government Institutions (AEGIS). For a discussion of “stripping” and the government’s response to the scandal, see Chapter 4 of Claire Hilton’s **Improving Psychiatric Care for Older People: Barbara Robb’s Campaign 1965-1975**, published in London by Palgrave Macmillan in 2017

136

Originally published in the June 1967 issue of **The Responaut** (Vol:4; Issue 2)

137

A slang term, coined by the journalist Ann Armstrong, to describe people who use machines to help them breathe

138

The film in production when this piece was written became **Words Without Hands**. For information on its making and funding see Tony Baldwinson's **Le Court Film Unit** (pages 10-11)

139

Hampton Inskip, a trustee of the Cheshire Foundation and the editor of **The Voice of the Disabled**, was sympathetic to the residents' demands for greater autonomy within the Cheshire Foundation and more say over its policies and how it was run. As Hunt makes clear in this letter, he was seen as one of the few allies the residents had high up in the organisation.

140

These notes were attached to the letter printed above

141

First published in the Winter 1969 issue of **The Cheshire Smile** (Vol: 15; Issue: 4)

142

Doreen Swift was the Sister-in-Charge at Le Court's East Wing – introduced in 1967 for new residents with intensive care needs. The article Hunt is discussing here is her 'Caring for the severely disabled' in **The Cheshire Smile** in Autumn 1969 (Vol: 15; Issue 3. Pages 18-22). The article is in part a description of the East Wing – the kind of people who live there, the building's layout, and the work staff do there – and in part a discussion of how to 'Cheshirise' residents who have just moved into Le Court from a long-stay hospital. Swift is particularly concerned with questions of how to bring new residents into the community that already exists, and of how to encourage them to take advantage of the opportunities and activities available in the Home.

143

First published in **The Architects' Journal Information Library** (27th May 1970) as one of several views requested by the journals' editors on the design of the Drummond's Centre for Spastics in Essex, a residential institution run by the Spastics Society. In the previous issue of the journal, an anonymous author had critiqued the centre's design as encouraging staff to act in authoritarian ways, and restricting residents' rights to privacy

and to choose who they socialised with. The journal agreed to publish letters from the Spastic Society's chief psychologist, the Matron of Drummond's, and two residents of the centre arguing that these claims were wrong. For the sake of balance, the editors also invited a comment from Hunt in the same issue. See the editorial notes on pages 1313 and 1321-22 of the May 1970 issue.

144

[Goffman, E. **Asylums** Hamondsworth, 1968, Penguin Books. Page 4]

145

[Townsend, P. **The Last Refuge** London, 1964, Routedledge and Kegan Paul. Page 447]

146

[As above. Page 69]

147

[As above. Page 114]

148

[As above. Page 99]

149

[As above. Page 96]

150

[As above]

151

[i.e. More money spent on land, buildings, and equipment]

152

Published in **The Guardian** newspaper under the title 'Bringing the disabled into view'

153

It's unclear if David Cohen was a journalist who had written a story for the paper, or simply another writer to the letters' page

154

What Hunt describes here is very close to the Fokus Society's housing program in Sweden. See "**Fokus Housing Scheme, Sweden**" in this volume.

155

First published in the Autumn 1972 issue of **The Cheshire Smile** (Vol:18; Issue 3)

156

This approach comes from Miller's previous research into the textile industry in India and manufacturing in the United States, rather than as a method designed specifically for institutions and the relationships within them. A brief description of the Open Systems Theory of organisations is provided by the Organization Person Group, which is influenced by Miller's work, [here](#)

157

'Social death' is a concept from sociology which describes how some people, or groups of people, are treated as if they dead while they are still alive. Examples of social death can include: treating someone as if they do not have a personality or ignoring their wishes; deciding that a group of people have no role to play in wider society; treating people as if they cannot have meaningful relationships with anyone outside their specific group (in family, work, or friendship groups); or preventing a group of people from having the same choices as everyone else (to work, vote, marry, etc). Social death was first used to describe the social position of black people in the American South during the 19th century and Jewish people during the Holocaust; but during the 1970s and '80s it began to be used to describe institutionalised older and disabled people, and people with mental distress.

158

'Horticulture' is the care of plants. In Miller and Gwynne's metaphor, this approach involves helping residents to emotionally 'grow' within the limits of the institution – in the way a plant can grow and flower to a limited degree in a plant pot or a greenhouse – by providing them with care and attention as individuals.

159

i.e. support residents' need for other people for either physical or emotional and psychological reasons

160

Stigma (London: Penguin Books – 1968. Pages 163-164)

161

See notes on Comment – Winter 1967 above

162

In this context, 'pathological' refers to something caused by an illness or disease.

163

'Defence mechanisms', first described by the psychoanalyst Sigmund Freud in 1894, are the ways the human mind avoids uncomfortable truths by either ignoring them or coming up with false beliefs. This can take the form of jokes (where something true is never thought about fully, but made fun of), implausible beliefs about yourself and the world (for example, that skin cancer or being in a car crash could 'never happen to me'), or making a story about your life which the uncomfortable truth doesn't fit into (for example, believing that you could not have hurt someone's feelings, because you're a very sensitive and polite person)

164

'Natural selection' is the biologist Charles Darwin's theory of why some species survive and others go extinct. In crude form, Darwin argues that animals which are better at adapting to a changing natural world are more likely to survive than those that don't. While Darwin's theory was only ever designed for plants and animals, his followers in the 19th century began applying 'natural selection' to human groups: arguing that black, disabled, gay and Jewish people, and women in general, were less able to adapt to the world and therefore inferior to white, European men.

165

In the Calvinist branch of Protestant Christianity, God has already chosen which people will go to heaven and which will go to hell before anyone is born. The people chosen for heaven are called 'the elect', and are morally superior to those going to hell – regardless of whether the elect lead a bad life or the non-elect try to become good people. Hunt is here making fun of Miller and Gwynne's claims to be scientific; by claiming that disabled people

are dependent and inferior simply because they're physically impaired, and by ignoring alternatives to the institution, what Miller and Gwynne are doing is closer to asserting a religious belief than it is to doing a scientific investigation.

166

First published in the Winter 1972 issue of **The Cheshire Smile** (Vol: 18: Issue: 4)

167

Louis Battye was a resident at the White Windows Cheshire Home in Sowerby Bridge, Yorkshire. Battye was a writer who published several novels throughout the 1960s (including **Cornwall Road**, **Dark at Seven** and **I Had a Little Nut Tree** – all published by Secker and Walburg in London). He regularly wrote comment pieces and poetry for **The Cheshire Smile**.

168

Hunt is referring to Battye's 'Comment' article in the Summer of 1972 in **The Cheshire Smile** (Vol: 18; Issue: 2. Pages 8-9). Battye argues that the Foundation has a poor reputation amongst working class people – particularly in the North of England – partly because its management are almost entirely middle aged and upper middle class. By inviting trade unionists, young people, and immigrant workers into the Management Committees, Battye believed that the Cheshire Foundation could convince its neighbours that it was a progressive and democratic force in society, and that Homes would become more a part of the community in the towns they were in.

169

First published in the newspaper **Social Services** (24th March, 1973), reprinted under the title 'Homes or homes?' in **The Responaut** in June 1973 (Volume 10: Issue 3)

170

Alf Morris (1928-2012) was the Labour Party MP for Wythenshawe in South Manchester, and the mastermind behind the Chronically Sick and Disabled Person's Act (see footnote below). He worked closely with disability campaign groups – including DIG and the National Campaign for the Young Chronic Sick – throughout the 1960s, and was made the first Minister for Disabled People in 1974

171

Sir Keith Joseph (1918-1994) was at this time the Conservative Minister for Social Security – which put him in charge of spending decisions on welfare and social services.

Joseph went on to become a close political ally of Prime Minister Margaret Thatcher, serving as her Minister for Industry and Trade at different points in her government, and heading up her policy research unit.

172

The Chronically Sick and Disabled Person's Act, which became law in 1970, was an ambitious piece of legislation which moved responsibility for housing and supporting disabled people from hospitals to local councils, made it compulsory for new public buildings to be adapted for disabled people, and committed the government to help local councils to make mobility and other aids available. Some of the wording was very vague, however, and the government didn't make any extra money available for councils to fulfil their new obligations. As a result, the housing, services, and changes to the built environment that disabled people saw varied a lot between different areas. The only nationally significant change to disability services was the rapid growth of day-care centres around the country, paid for by local councils. While these probably prevented many disabled people from going into institutions, they were still segregated facilities rather than focussed on disabled people's integration into the communities they lived in (see Ann Shearer's **Disability, Whose Handicap?** Pages 99-100)

173

No other records of this seminar survive

174

Sections 9-16 of the Chronically Sick and Disabled Person's Act outline the structure of 'advisory committees' for services disabled people use. These were to include disabled service users, alongside parents, carers, and interested professionals (doctors, social workers, etc). These were never legally required, but the Act encouraged councils to use them wherever the council felt it was possible to do so.

175

Regional Hospital Board

176

Professor Sven-Olaf Brattgard (1921-2001) was a professor at the Centre for Study of Handicap at Gothenburg University in Sweden, and a founder member of the Fokus Society – an early independent living scheme in Northern Europe. See the next article and its footnotes.

177

This text first appeared as minutes of the meeting compiled and circulated by the Central Council for the Disabled.

178

Swedish Kroner

179

It's unclear if Mr Gordon was a resident at the Hertfordshire Home, a member of staff there, or a member of the Management Committee.

180

The Royal Star and Garter was an independent care home for wounded and disabled soldiers, established in Richmond, Middlesex, in 1917

181

Section 4: Controversy at its Best

This column was published in the Autumn 1966 edition of **The Cheshire Smile** (Vol: 12; Issue 3)

182

Sheila Ridley was a novelist who lived at Marske Hall Cheshire Home in Teesside in the early 1960s. Ridley wrote romance fiction, usually with a nurse as the central character. Her works include **Nurse in Doubt** in 1963, and **Nurse in Danger** in 1967 – both published by Hale Publishers, London. While Ridley published two articles in **The Cheshire Smile** in 1963, she certainly didn't write anything like a regular column for the magazine, and neither of her pieces have 'Comment' as a title. It is possible, however, that she wrote regularly for another publication. One of her pieces in the **Smile** – 'Speaking for myself' (Vol: 9; Issue: 3. Pages 36-7) – is republished from **Magic Carpet** and has the style of a newspaper column – jumping between various subjects as they have cropped up

in the last few weeks of the author's life.

183

Social Service Quarterly was the journal of the National Council of Social Service, an organisation representing small independent charities (now called the National Council of Voluntary Organisations – NCVO)

184

Hunt does not provide a title, author name, or issue number for the article in question.

185

This appears to be a typo, either by Hunt or by the editors of **The Cheshire Smile**. It is possible that Hunt either meant to write 'irredeemably' or 'irremediably' (i.e. without the hope of a cure). Both words imply that non-disabled people think that their disabled peers as inevitably inferior to them.,

186

Published in the Winter 1966 edition of **The Cheshire Smile** (Vol: 12; Issue: 4)

187

The National Cripples' Journal was an independent magazine based in Coventry. It was primarily a campaigning journal, with many articles by disabled people putting forward reforms to how housing, benefits, and education were organised for disabled people, and many editorial columns critical of the government. The journal changed its name to **The Voice of the Disabled** in 1968, and went on to have a close relationship with Hampton Inskip – one of the trustees of the Cheshire Foundation. **The Voice of the Disabled** was one of the journals that Hunt wrote to in 1972 to invite disabled people to join UPIAS

188

The Responaut was a quarterly journal for people who use portable respirators (medical equipment to help them breathe). It was edited by the journalist Ann Armstrong (real name Doris Page), who used a respirator herself, and whose policy was to commission as many articles by respirator users and other disabled people as possible. The back catalogue of the Responaut can be found on the [Ann Armstrong Archive](#)

189

M.S. News was the newsletter-cum-magazine of the Multiple Sclerosis Society – founded

by Sir Richard Cave and wife Mary. Despite Mary Cave having multiple sclerosis, the Society has never been user-led and remains a traditional style charity.

190

It's very difficult to find archives of, or any information about, this journal. It may have been published by the Muscular Dystrophy Campaign, founded in 1959 to fund research into muscle wasting conditions and to campaign for experimental treatments to be provided by the National Health Service.

191

Physiotherapy was the professional journal of the Chartered Society of Physiotherapists

192

The British Journal of Occupational Therapy was (and is) the professional journal of the Royal College of Occupational Therapists

193

Medical Social Work was the journal of the Institute of Medical Social Workers (IMSW). The IMSW was one of the organisations that went on to form the British Association of Social Workers – which is currently the main professional body in the sector.

194

The British Council for the Rehabilitation of the Disabled was a medical association, bringing together doctors and surgeons in the British Isles to share research and problems from work with their patients.

195

The Central Council for the Disabled was a small charity formed in the inter-war years – initially to raise money and provide services for disabled children. While never particularly large in its number of members or volunteers, and not particularly active in providing services, the Council was given oversized importance by Harold Wilson's Labour Government, who ensured it was given a seat on the All-Party Parliamentary Group which looked at disability issues. The Council eventually merged with the British Council for the Rehabilitation of the Disabled in 1977 to form the Royal Association for Disability and Rehabilitation (RADAR)

196

T.J. Nugent was the Director of the Rehabilitation Centre at the University of Illinois in the USA. In the article Hunt mentions here, Nugent argues that the reason rehabilitation fails to bring people into mainstream life is because it is limited to the hospital – leaving disabled people segregated if they are unable to live in a totally inaccessible environment. He argues that rehabilitation should be accompanied by adaptations to schools, workplaces, and public buildings, which would give rehabilitation patients a much greater chance of reducing their dependency on others and living the same kind of lives as their non-disabled peers. See 'New avenues for life' in **The Cheshire Smile** (Vol: 12; Issue 3. Pages 14-15)

197

Published in the Spring 1967 edition of **The Cheshire Smile** (Vol 13: Issue 1)

198

Paul Driver was a resident at Athol House Cheshire Home in southeast London, who often wrote poetry for **The Cheshire Smile**. Driver's letter states his agreement with Hunt that residents should be involved in the running of the Cheshire Foundation, arguing that 'when your arms and your legs have packed up on you, a major administrative decision is just about the one thing left that you can make. Only you won't be asked to'. See **The Cheshire Smile** – Vol: 13; Issue 1. Page 8

199

Dudley Kitching lived at the Kenmore Cheshire Home in Yorkshire, and wrote occasionally for **The Cheshire Smile** on local news concerning the Foundation. The letter Hunt references here appears not to have been published.

200

Cassandra is a Trojan prophetess from Ancient Greek and Roman mythology. She is given the gift of seeing the future by the God Apollo in exchange for a promise to marry him. When she refuses his advances, Apollo puts a curse on her so that nobody will believe what she tells them. There are different versions of the Cassandra myth, but in all of them she predicts that a plan by the king of Troy will end in disaster and is ignored. The city is destroyed, its inhabitants massacred, and Cassandra is forced into slavery by the invading Greek army.

201

This letter also appears to be unpublished, apart from extended quotes by Hunt in this piece.

202

Published in the Summer 1967 issue of **The Cheshire Smile** (Vol: 13; Issue 2)

203

Scrutiny was a series of documentaries produced by the BBC, and broadcast between 1966-67. It was presented by Derek Hart.

204

War on Want is a left-wing anti-poverty charity, founded in 1951. It is closely related to social movements in Britain and abroad, including the trade union and peace movements, and (more recently) civil rights movements of indigenous people in the global south.

205

Beatrice Wright (1917-2018) was an American psychologist. **Physical Disability – A Psychological Approach** was published in 1960 by Harper and Row publishers in New York, and was an early attempt to explain how disabled people psychologically 'adapted' to their impairments. The original book is currently out of print, but a heavily revised second edition (**Physical Disabilities – A Psychosocial Approach**) was published in 1983 (also by Harper and Row) and is still available.

206

First published in the Autumn 1967 edition of **The Cheshire Smile** (Vol: 13; Issue 3)

207

The Williams Committee – named after its Chairperson Professor Gertrude Williams – was a research body set up by the National Council of Social Service;. The Williams Committee was asked to investigate why residential and nursing homes, long-stay hospitals, and institutions for people with mental health difficulties had such a problem hiring and keeping enough workers. Their final report was published by Allen and Unwin in London in 1967

208

See 'Caring for the Carers' by Dr. Margaret Agerholm in **The Cheshire Smile** (Vol: 13; Issue: 3 – pages 12-13)

209

First published in the Spring 1968 issue of **The Cheshire Smile** (Vol: 14; Issue: 4)

210

Selwyn Goldsmith (1932-2011) was a disabled architect, town planner, and commentator on disability issues, and is largely credited with creating the idea of 'universal design' – a project where buildings and spaces are designed so that, in principle, they could be adapted to meet any kind of access need. For more information about Goldsmith, see the **Editor's Introduction** in this volume

211

At the time, this idea seems to have been most associated with the American National Federation of the Blind (NFB), who felt so strongly that there should be no 'special' adaptations to mainstream services that they opposed a legal action by other blind activists against New York's Metropolitan Transit Authority (MTA) in the early '60s. The MTA had bought new carriages without gates, making it impossible for white cane users to tell the difference between the doorway and the gap between the carriages. Many blind commuters fell between the carriages while trying to board the train, several dying as a result. The NFB argued that to restore the carriage gates just for blind people would be patronising and a threat to the idea of independent travel, and that what was needed instead was for blind people to be better trained to use the new carriages safely. For an overview see pages 22-4 of Doris Zames Fleischer and Frieda Zames' **The Disability Rights Movement: From Charity to Confrontation** (published in 2011 by Temple University Press in Philadelphia)

212

i.e. Frank Spath's 'Editorial' in **Cheshire Smile** (Vol: 14; Issue 4)

213

Stirling Moss (1929-1990) was a famous English racing car driver. While Moss was involved in promoting adapted cars later in his life, I've been unable to find any public information about his involvement with the disabled motoring scene at the time this article was written.

214

Invalid tricycles (or 'Noddy cars' as they were known because they looked like a vehicle from the children's TV programme **Noddy**) were three-wheel adapted vehicles with all steering and breaking controls operated by hand. The Ministry of Health provided them for disabled people (often veterans from the Second World War) at a very reduced price

between 1948 and 1978. The tricycles were initially a revolutionary change in many disabled people's lives; for the first time, they offered a way of travelling independently to people who would otherwise be excluded by inaccessible public transport or cars built for non-disabled people. As time went on, however, limitations of the tricycles became apparent. Their strange balance, combined with a soft fabric roof, raised safety concerns, and it was both uncomfortable and technically illegal for a passenger to ride along with the driver. Most models also had remarkably small engines, and consequently were banned from motorways.

215

Nothing is known about Nigel Harvey beyond the article Hunt quotes here.

216

Harvey's proposal was not adopted by the DDA, whose campaigning on issues other than personal transport was kept inside the Joint Committee for the Mobility of the Disabled. See Judy Hunt's **No Limits** (pages 79-80)

217

Which? is a consumer rights magazine which launched in 1957. Aiming to improve the quality and value for money of goods and services in Britain, and to empower consumers to make informed decisions about what they buy, the magazine compares the merits of different goods, highlights poor manufacturing or companies who rip off customers, and runs a number of awareness campaigns around product safety

218

Published in the Spring 1969 edition of **The Cheshire Smile** (Vol: 14; Issue: 1)

219

This book is currently out of print

220

Schontz (1926-2015) was professor of psychology at the University of Kansas. His main areas of research were somatopsychology (or, the influence of diseases or impairments on a person's mental state) and the psychological effects of rehabilitation practices (occupational therapy, physiotherapy, etc)

221

An idea like this had already been raised by Margaret Agerholm at the 1967 Conference of the Cheshire Foundation, where she argued that the relatively free and liberal environment of a Cheshire Home would likely be a better environment than a hospital to support recently disabled people to regain physical function. Her proposal was roundly rejected, with Leonard Cheshire setting himself dead against it. Cheshire argued that the Homes were designed to house people who had no hope of integrating into mainstream life, and that the Foundation would 'lose some of our spirit' if it concerned itself with people who could go on to live independently. See the 1967 Conference Report in **The Cheshire Smile** (Vol: 13; Issue 4.)

222

In defence of Cheshire's position (see footnote above), some members of Management Committees for the Cheshire Homes argued that there was no need for physical rehabilitation as they were already rehabilitating the souls of their residents – by bringing them into a community, teaching them the virtues of charity, etc. See 1967 Conference Report

223

Section 5: Writings on DIG

A theme in some DIG press-releases and statements

224

See Hunt's **Comment – Autumn 1968** in this volume, alongside the articles in this section, for his statement of this view.

225

First published in the Spring 1967 issue of **Christian Action**

226

It is likely that this letter was sent to DIG for use in one its press releases. The author is unknown (and probably anonymous)

227

For a discussion of Supplementary Benefits during the mid-60s; see Jameel Hampton's **Disability and the Welfare State in Britain: 1945-1979** (Pages 54-57)

228

Published in the Summer 1969 edition of **The Cheshire Smile** (Vol: 14; Issue: 2)

229

This pamphlet is currently out of print. Copies are available to view in the Modern Records Library at the University of Warwick in Coventry

230

A White Paper is a discussion paper prepared by the Government for Parliament, in which it outlines its policy on a particular issue. It is best thought of as an early step towards passing a law or laws – setting out what kinds of thing the government intends to do to get an idea of how MPs, the public, and people working in that area respond. A summary of this White Paper is provided in the May 1969 issue of **Bulletin** magazine, and is available online [here](#)

231

Richard Crossman (1907-1974) was at best lukewarm towards disability issues during his time as Secretary of State for Social Security. Crossman had come into the job on the back of his proposals for reforming the pensions system in Britain. This was a big and complicated job, and Crossman was frustrated by campaigns which tried to distract him from it by making him deal with non-pensions issues – whether they be disability or child poverty. For a short overview of Crossman's attitudes towards a disability income, see pages 79-81 of Gareth Millward's (2014) **Invalid Definitions, Invalid Responses: Disability and the Welfare State, 1965-1995** – published by the London School of Hygiene and Tropical Medicine

232

The National Assistance Board was the government agency which decided whether unemployed people were entitled to additional ('Supplementary') benefits – usually either because they were extremely poor, or because their unemployment was not their fault

(because of impairment, because their job had disappeared, etc). The Board, which in practice was a collection of local committees, had very few hard and fast rules as to who should and who should not receive extra benefits – so applying for help from them is what we'd today call a 'postcode lottery', with certain areas being much more generous than others. The money they were able to give out, however, was always very small in amount. The process of applying was also very stigmatised, as it involved the claimant explaining to a group of strangers how helpless and poor they were.

233

Published in the Autumn 1969 issue of **The Cheshire Smile** (Vol: 14; Issue: 3)

234

The Constant Attendance Allowance was an 'extra cost' benefit to pay for care services in a disabled person's home, and was brought in by the Conservative Government in 1970. Attendance Allowances were already part of benefit schemes for disabled war veterans or people who became impaired through their work, and DIG had been pushing for them to be expanded to all disabled people. The Attendance Allowance was the first benefit for disabled people that wasn't based on whether or not they had paid taxes through their work; but in reality it was designed only to be given to a small portion of disabled 'civilians' and was paid at a much lower rate than for ex-military or industrially injured people .

235

First published as a chapter in **The New Poor: Anatomy of Underprivilege** (edited by Ian Henderson) in 1973. Reproduced by kind permission of Peter Owen Publishers

236

[Peter Townsend, *The Disabled in Society* (Greater London Association for the Disabled, 1967). Lecture based on a survey of 211 men and women registered as physically handicapped with local authorities in London, Essex and Middlesex. A detailed report of the survey, by Sally Sainsbury, was published by the GLAD in December 1970.]

237

[S. Goldsmith, *Designing for the Disabled* (RIBA, 1967), p. 54.]

238

[Townsend, *op. cit.*, p. 1.]

239

[Amelia Harris, *Handicapped and Impaired in Great Britain* (HMSO, 1971), vol. i. Judith R. Buckle, *Work and Housing of Impaired Persons in Great Britain* (HMSO, 1971), vol. ii.]

240

[Although the survey provides much useful information, some vital questions were not covered, and the main section on income is still not published.]

241

[Until her death in a road accident in 1969, Mrs Du Boisson's legendary charm and determination were a major factor in the Disablement Income Group's rapid growth.]

242

[DHSS figure quoted in *Creating a National Disability Income* (DIG Occasional Paper 12, 1972).]

243

[Townsend, *op. cit.* pp. 18-19]

244

[Frank W. Skinner (ed.), *Physical Disability and Community Care* (Bedford Square Press, NCSS, 1969). Survey of 201 people registered with the Borough of Tower Hamlets as physically handicapped.]

245

[It should be noted that two-fifths of the Townsend sample, and half of that in Tower Hamlets, were aged 65 or over. The few available income figures from the 1968-9 Government survey, with again nearly half those interviewed being elderly, confirm the picture of widespread hardship.]

246

[Townsend, *op. cit.*, pp. 9-11.]

247

[Skinner, *op. cit.*]

248

[Encouragingly, their 1972 policy Green Paper seems to accept the principle of a disability benefit payable as a right and based on need rather than on contribution record. It remains to be seen, however, what happens to the proposal as it is spelled out in more detail.]

249

[Unhappily, DIG's proposals involve the acceptance of earnings-related disability pensions, which in my view would mean the further creation and perpetuation of inequalities and anomalies. Purely in cash terms, too, earnings-related benefits would be ineffective; their value would tend to be small because of the low earnings associated with disablement, and they would in any case be paid only to a small minority of the disabled]

250

The Contributions Adjusted National Disability Income (CANDI) was DIG's leadership's proposal for the policy it should be recommending to the government. Unlike DIG's earlier calls for a National Disability Income, the CANDI proposal would be linked to the tax somebody had paid – meaning that people who had always been discriminated against in employment would receive a lower pay out than someone who had only recently become impaired, and had been working full time before then.

251

Jimmy Martin was an eight year old boy from Leicester, who was born with one leg and no arms. He was turned down for the higher rate of Constant Attendance Allowance because, although the doctors assessing him accepted that he needed support during the day – he tended to sleep well through the night. His parents believed that this kind of decision punished parents of disabled children who worked hard to make their child feel safe and secure, and their local MP Greville Janner raised the case in the House of Commons.

252

'Thalidomide Children' refers to children born with congenital impairments after their mothers consumed the medicine Disatavil (containing the chemical thalidomide) to treat morning sickness. During the early seventies, parents of 500 or so children sued Distavil's manufacturer, but as the company was based in Germany getting compensation through the courts was a long and expensive process. There was public outcry that the families of these children were faced with extra-costs because their child had an impairment, but hadn't received any financial support. By 1973, it had become clear that the government intended to find some way to get money to the families, eventually opening a Fund (with a

limited amount of money) in 1974 for families where a child had a congenital impairment. Many in DIG were frustrated that the organisation hadn't used this opportunity to push for a comprehensive disability income for all disabled people.

253

[The Disability Trap]

254

This presumably refers to a discussion paper or press release prepared by DIG or one of its members – although nothing called either 'The Poverty Trap' or 'The Disability Trap' is cited in either Gareth Millward or Jameel Hampton's work on DIG

255

A Question of Confidence was part of a series of talk shows made by the BBC in 1972-3, in which members of the public asked politicians questions. Unlike previous political talk shows, the producers took a very hands-off approach to managing the discussion – leading to a panel of six MPs from the Labour, Liberal and Conservative Parties being subjected to very hostile questioning from a large audience. The MPs were so upset that they sent a letter to the BBC demanding the program's producer be sacked. The BBC didn't oblige, but did apologise very publicly to the politicians involved. It appears from this piece that DIG also reprimanded one of their members for taking part, although I haven't found any account of this elsewhere.

256

The Mental Patients Union was a group of mental health service users demanding an end to compulsory and irreversible treatments for psychiatric patients. They were founded in London in 1973, later changing their name to the Campaign Against Psychiatric Oppression

257

The National Federation of Old Age Pensioners' Associations was founded in 1912 as the campaigning arm of local pensioners' welfare groups. It changed its name to the National Pensioners' Convention in 2000

258

Claimants' Unions are organisations where people who use benefits or welfare services use confrontational action and peer support to solve each others' benefit problems and pressure the government to reform the welfare system. The first Claimants' Union in Britain

was started in Birmingham in 1969 and, at the time of this paper, the Unions were fighting for significant reforms to Supplementary Benefits.

259

The Bill Hunt is referring to went on to become the Pensions (Increase) Act 1974; which linked some parts of the state pension system to how much tax a person had paid during their working life.

260

See Peter Townsend's 'Enabling the disabled' (**The Guardian** – May 2nd 1973)

261

See Tony Lynne's 'Disabled income' (**New Society** – May 3rd 1973). Lynne's article was circulated in the pre-conference papers alongside Hunt's paper

262

Section 6: UPIAS

See page 2 of Baldwinson's [Research Notes: UPIAS](#) published by TBR in 2019

263

Quoted in Gareth Millward's 2014 PhD Thesis **Invalid Definitions, Invalid Responses: Disability and the Welfare State, 1965-1995**: London School of Hygiene and Tropical Medicine (page 128)

264

First published in **The Guardian** newspaper

265

Ann Shearer was the Welfare Correspondent for **The Guardian**. She became interested in disability and deinstitutionalisation in 1968, after reporting on neglect and abuse at a long-stay hospital for children with learning difficulties. She went on to write a book (**Disability, Whose Handicap?** – published by Blackwell in London in 1981) which argued that disabled people are more often excluded from mainstream life by social attitudes and barriers than by their impairments

266

The Campaign for the Mentally Handicapped (or CMH) was started by the parents of children with learning difficulties and some staff from long-stay institutions who wanted to see the system changed. Unlike other campaigning groups at the time, the CMH was very radical in its demand to the closure of all segregated housing and schools for people with learning difficulties. Ironically, it was largely funded by the Spastics Society – which itself ran segregated residential homes and colleges for people with cerebral palsy. The CMH's first conference, which looked at how professionals and people with learning difficulties could work together to design new services, was remarkable in that the vast majority of delegates were disabled people rather than parents or professionals. For a brief overview of this conference and the early years of the CMH, see Ann Shearer's 2021 essay [Awed by the Human Spirit](#).

267

First published in the Winter 1972 issue of **The Cheshire Smile** (Vol: 18; Issue 4): this version was subsequently published in the Disabled Drivers' Association's magazine **The Magic Carpet** in early 1973 (Vol: 25; Issue 1), and in **The Voice of the Disabled** (Vol: 159)

268

Published in UPIAS's **Internal Circular: 3** in 1973 (month of publication unknown)

269

Published in UPIAS's **Internal Circular 4** in 1973 (month of publication unknown)

270

Finkelstein's 'Contribution to the Discussion on the Nature of our Organisation' (in **Internal Circular 3**) put forward an early version of the social definition of disability based on the three terms used by the Office of Population, Censuses and Surveys to describe disablement: impairment, handicap, and disability. Finkelstein argued that, while doctors had expertise on bodily illness and abnormalities (impairments), they had tried to 'dominate' the field of disability by claiming special knowledge and power over other parts

of disabled people's lives and experience. This included what Finkelstein thought were properly social problems (such as the design of buildings, unemployment, or the kinds of support available), but also technical problems that were not strictly medical. There is, Finkelstein argued at the time, a difference between physical impairment, social disability, and something he called **handicap** – the loss of functional ability linked to an impairment (such as being able to lift a cup with an upper-body mobility impairment, or to see people in the distance with a sight impairment). Finkelstein argued that the techniques and technologies which minimised or corrected these abilities were already largely held by professionals who were not doing medicine, but were forced to take their orders from doctors anyway – preventing them from properly working out how to develop their skills and knowledge to better support disabled people's integration. Therefore, he argued, disabled people as a whole had an interest in supporting these workers in their struggle to break free of medical influence.

271

In the same article, Finkelstein argues that even those building segregating institutions describe themselves as being 'for integration' in general, but insist that the people they are housing are the exception to this rule (because they are 'too disabled', or have particular personal problems, etc). By putting, 'against segregation' in the Union's name, Finkelstein believed that the Union would make it clear to disabled people that it will not accept these kinds of arguments.

272

A quote from Finkelstein's 'Contribution to the Discussion of the Nature of our Organisation'

273

Published in UPIAS's **Internal Circular 5** in 1973 (month of publication unknown)

274

Member D had written a response to the first two UPIAS Circulars which was published in **Circular 4** (1973, month unknown). His piece covered a number of issues (including responses to a questionnaire sent out when UPIAS was first formed and comments on other members' articles), but contained three points that Hunt and other members ending up debating at length. The first of these was Member D's rejection of 'oppression' as a description of disabled people's situation in wider society, based on the fact that Member D himself didn't 'feel' oppressed. The second is a claim that the Union could only work through what he called 'democratic means' – joining government advisory committees and working groups, or committees linked to charities as DIG had done, rather than antagonising those with power or making more radical demands. For this, Member D argued that the Union needed a strong figurehead who could represent all members when dealing with government or charity officials, along with a number of spokespeople to attend

meetings about disability policy. Finally, Member D proposed that the Union should not have any specific analysis or, or policy towards, segregated institutions; arguing that, while he personally didn't support them, they did not affect the majority of disabled people and that many residents preferred them their previous lives in mainstream society. For a separate response to this argument, see Vic Finkelstein's **Are we Oppressed?**

275

While rightly seen as an insulting and demeaning term now, 'mentally retarded' was a commonly used medical name for people with learning difficulties in the 1970s. As Hunt shows in the next sentence, he is opposed to the view that people with learning difficulties are in way inferior to people with physical impairments.

276

This refers to a section in Member D's article where he reports that workmates who need to ask him a question would address it to the colleague sitting next to him.

277

While an insulting term nowadays, 'negro' was both in common use at the time and, at least during the early 1970s, was a preferred term for certain sections of the black civil rights movement in the USA (see, for example, writing by James Baldwin, James Boggs, and Howard Cruz from the time)

278

i.e. pieces of legislation like the Chronically Sick and Disabled Person's Act (1970)

279

First published in UPIAS's **Internal Circular 9** (June 1974).

280

The Spinal Injuries Association (SIA) was founded in 1974 to provide information and advice for people with spinal injuries, and to represent their views in discussion with government and health service officials. Unlike the disability charities existing at the time, the SIA's constitution stated that it had to be controlled by people with spinal injuries – who had to make up the majority of any committees making decisions about how the organisation was run or what it did. For a brief history of the SIA see Frances Hasler's article 'Developments in the disabled people's movement' in the 1993 edition of the book **Disabling Barriers – Enabling Environments**, published by the Open University Press in Milton Keynes

281

The Brittle Bones Society was a charity formed to provide peer support and awareness raising for people (particularly children) with Osteogenesis Imperfecta (OI). While it never claimed to be an organisation **of** disabled people in the sense that it would always be entirely run by people with impairments; in practice the majority of its early members were either people with OI or their immediate family (See the documentary film [Brittle Bones Society at 50](#))

282

This draft of UPIAS's **Aims and Policies** was circulated to members in July 1974 ahead of UPIAS's founding conference at the end of the year. This draft was first published in 2019 in Tony Baldwinson's **Research Notes – UPIAS** (pages 32-46). The final policy statement, agreed at the 1974 conference, is hosted [here](#). For discussion of the draft by UPIAS members see: Baldwinson's **Research Notes** (pages 41-42) and Vic Finkelstein's **Are We Oppressed?**. For a report of the first conference, see Baldwinson's **Research Notes** (pages 47-59).

283

Concorde was a supersonic aeroplane (meaning that it could fly faster than the speed of sound) that was jointly developed by the British Aerospace Company and the French company Sud Aviation. The project was extremely expensive, and heavily subsidised by the British government. It was clear at the time that this draft was written that the project was overrunning, and well over budget. Shortly after this draft was written, Concorde's makers announced that it might cost them a staggering £2.1 billion (£13.2 billion in 2020 prices) just to get the first planes made.

284

Centre Point was London's first skyscraper, standing at 385 feet tall and overlooking Tottenham Court Road Tube Station. The building was completed in 1966, but its owner Harry Hyams decided that the project was only profitable if he could sell it all at once to a single buyer. This resulted in the building standing completely empty while London's homelessness crisis got worse. In 1974, housing activists occupied the empty building to protest what they saw as a housing policy which cared more about profiting the rich than housing the poor.

285

First published in UPIAS's **Internal Circular: 13** (December 1974)

286

Member E lived in an institution in which she was the only person in the Union. She was concerned about what would happen to her – and others in her position – if care staff discovered that she was a member of an organisation critical of the way care was carried out. She suggested, in **Circular: 13** that the Union's first task should be a form of peer-support where members were able to give each other advice and reassurance on how to manage tricky situations with staff in institutions. Unfortunately, a few months after she wrote this article, somebody did inform the institution's management that Member E was in UPIAS, and the situation became so difficult for her that she felt she had to resign from the Union.

287

For an account of the struggles at Pearce House, see Maggie Davis and Ken Davis's **To and From Grove Road**, published by TBR in 2019

288

Hunt is here referring to the economic and social crisis of 1973-75. After a massive increase in the price of oil, the British government decided that most businesses could only use electricity on three days in a week – leading to a huge increase in unemployment. As most goods or services need energy based on oil to be made or transported, prices for everything rose rapidly – meaning that both people's and the government's savings were worth much less than before. Workers, particularly coal miners, went on long, drawn out strikes to try and make their wages match these high prices. At the same time, it became very difficult for either Labour or the Tories to form governments, and from 1973 until 1979 there were frequent changes in which party was in charge.

289

The M.S. Action Group was founded in 1974 by people with Muscular Sclerosis. It's aims were to campaign for more funding for research into treatments and cures, better welfare services, and against discrimination against people with MS (particularly in workplaces, schools and colleges).

290

For the debates around the desirability of the Invalid Tricycle as a form of transport for disabled drivers, see Hunt's **Comment – Autumn 1968** above

291

Originally published in UPIAS's **Internal Circular: 15** (April 1975)

292

Republished as **Are We Oppressed?** by TBR in 2018

293

See Hunt's **Policy Paper to the 1973 Conference of the Disablement Income Group** in this volume

294

Vic Finkelstein's **Do Deny or Not to Deny Disability**, originally published in the Winter 1974/5 issue of **Magic Carpet** and reprinted in UPIAS's [Information Pack for Members](#)

295

Originally published in UPIAS's **Circular: 15** (April 1975), **Circular 16** (June 1975) and **Circular: 18** (February 1976). Asterisks have been placed in this chapter between reproductions from each Circular.

296

Sir Christopher Foxley-Norris (1917-2003) was the Chairman of the Cheshire Foundation between 1974 and 1983, going on to serve as its President afterwards. Much like Cheshire himself, Foxley-Norris was a distinguished fighter pilot in the Royal Air Force during the Second World War, taking part in the Battle of Britain and various dogfights in the Aegean Sea in the second half of the conflict. After retirement from the RAF, Foxley-Norris continued his military career alongside his role with the Foundation, serving as the North Atlantic Treaty Organisation's (Nato's) chief military commander in Germany, and later its Head of Logistics. In addition to his work for Nato and the Cheshire Foundation, he also served as Chairman of the pro-tobacco lobbying group Forest

297

Carmel Short was the Secretary of the Leonard Cheshire Foundation between 1968 and 1977. An oral history interview with her, covering her time in the role, can be found on the [Leonard Cheshire Archives Website](#)

298

Tulse Hill is an area in South London

299

The Association of Disabled Professionals (ADP) is a self-help, peer support, and lobbying organisation of disabled workers in managerial and professional jobs, or seeking to get into them. It was started in 1971 by members of DIG's Executive Committee, and was one of the first Disabled People's Organisations to not be limited to a particular type of impairment, and to address disability issues within employment

300

The National Federation of the Blind (NFB) was established as a campaigning organisation of blind and partially sighted people in 1947 to work on the issues facing them people in the community. The NFB had always worked closely with charities for blind people – such as the Royal National Institute for the Blind and various local groups led by sighted people. At the time Hunt wrote this letter, the leadership of the NFB had come to the view that these charities were actually holding the NFB's campaigns (particularly on transport and benefits) back, and the NFB was considering starting a new national campaigning group made up only of organisations controlled by blind people. For an overview of this discussion, see the November 1973 edition of the NFB's journal **The Blind Advocate**. The NFB also sent a delegate to the discussion between UPIAS and the Disability Alliance, whose comments are published in Section 2 of **Fundamental Principles of Disability**.

301

Possum (Patient Operated Selector Mechanism) computers were invented in 1961 by volunteers at the Spinal Injuries Centre at Stoke Mandeville Hospital in England. The original devices were operated by mouth, and allowed people with very limited mobility to turn on lights, open doors or windows, make telephone calls, or use a typewriter by sucking and blowing on a tube placed near them.

302

A report of this conference was written up by two UPIAS members in **Circular: 11**

303

Hilary Pole (1942-1975) was a poet and essayist from Yorkshire. In her final year of college, Pole developed a rare condition called Myasthenia Gravis – which stopped her body being able to send the nerve impulses to her brain and made her unable to control her speech or the movement of her limbs. With an adapted Possum computer attached to her toe (the only part of her body she could fully control), Pole was able to continue to write articles and poems which were widely published in the national press. She was awarded an MBE (Member of the British Empire) by Queen Elizabeth the 2nd in 1972 for her contribution to literature

304

Reprinted as 'Co-ordinated rehabilitation' in the Summer 1970 issue of the **Cheshire Smile** (Vol: 16; Issue 2 – pages 6-10)

305

Shephard's untitled letter is published on page 8 of that edition (Vol: 20; Issue: 4)

306

Hydon Hill is a Leonard Cheshire Home in Goldaming, Sussex

307

Here the text becomes unreadable

308

This piece is extracted from the **Executive Committee Circular** of June 13th 1975. These circulars were private discussion pieces between members of UPIAS's Executive, and were only available to other members on request.

309

See the introduction to the **Role of the Residents** debate in this volume

310

Originally published in UPIAS's **Circular 16** in July 1975

311

An edited version of this article was originally published in **The Catholic Herald** in late 1977 (month of publication unknown). Hunt was disappointed with the editing of the published version, and the fact it was attributed to him personally rather than to UPIAS as he had requested. The text reproduced here is the unedited manuscript copy of the article, circulated in UPIAS's **Circular 21** (January 1978) with a covering note from Hunt warning other members of the 'way those of us who have had contact with press, radio and television find we are treated. While they want something from us, charm, sympathetic understanding and flattery are to the forefront, often with more or less subtle bribes being dangled as well. Once they've got what they want, our wishes no longer count and it becomes clear once again that their basic interest is in earning a living from exploiting people like us. (...) [It] shows up the importance of having our own means of publication so that we are free to say what we wish without suppression or distortion'

312

[Maureen Oswin. 'Holes in the Welfare Net' Bedford Square Press (National Council of Social Services)]

313

[**Fundamental Principles of Disability**, p.15 The Union of the Physically Impaired and the Disability Alliance Discussion document]

314

Grove Road was an adapted housing project in Nottinghamshire, which UPIAS members Ken and Maggie Hines were heavily involved in developing. The flats that made up the Grove Road project were adapted for wheelchair users, with non-disabled tenants providing low level support to their disabled neighbours in exchange for subsidised rent. The scheme became inspirational to other housing associations and disabled people's activist groups, with similar adapted housing-with-help schemes started in Lincolnshire and London in following years. The article Hunt is referring to here is Ken Davis's 'Tenant's eye view' in **Disability Challenge** (Vol: 1). See also Maggie Davis's **To and From Grove Road** published by TBR in 2019

315

[Alf Morris - A Personal Message, 4th September, 1974 **Cheshire Smile**, Autumn 1974, Vol. 20 No. 3. p.4]

316

The Warnock Committee (named after its chairwoman, the philosopher Mary Warnock) was set up by the Department for Education to report on how schooling could be improved for disabled children. Its report, published in 1978, argued for a complete overhaul of the segregated school system. Where before children with certain kinds of impairment automatically went to a special school, the Warnock Committee argued that the local mainstream school should have to prove that they could not meet the child's educational needs before special schooling was considered. These recommendations were made law in the Education Act of 1981

317

The Snowdon Working Party (named after its chairman Lord Snowdon) was a House of Lords research group set up to investigate the extent that disabled people were integrated into mainstream society. It published its report in 1977; noting that, amongst other things, the employment quota for disabled people from the Disabled Persons Employment Act of

1944 were not being met by either government workplaces or nationalised industry.

318

See **Comment – Spring 1968** above

319

[**The Handicapped Person in the Community**, Open University. Part 1. Units 9-10]

320

[Paul Hunt - Parasite People **Cheshire Smile**, Autumn 1972, Vol. 18 No. 3. p.15] – reprinted in this volume.

321

[**A Life Apart** - E.J. Miller and G.V. Gwynne. Tavistock Publications and Lippincott. 1972. p.124]

322

[p.23]

323

[p.6]

324

[p.8]

325

[p.7]

326

[p.8]

327

[p.21]

328

[p.72 15]

329

[p.226, 9, 223, 196]

330

[p.89]

331

The Open University, based in Milton Keynes, is Britain's largest distance-learning university – allowing students to study for a degree without moving to the campus. It specialises in professional courses and qualifications for people already in work.

332

[p.226]

333

[p.216]

334

[p.216]

335

'Splitting' is when someone decides that all other people are either 'good' or 'bad' to help them deal with a difficult emotion situation.

336

Collusion is where two people (usually a patient and their doctor) unconsciously work together to avoid addressing a difficult (usually psychological) problem. Collusion can also

occur in personal relationships where, for example, a married couple might find ways to 'talk around' the fact that one of them is having an affair.

337

Projection is when someone believes the unwanted feelings they have are actually held by someone else. An obvious example is when someone who feels insecure accuses someone else of being jealous of their success

338

[p.121]

339

Electroconvulsive Therapy; a procedure where electrical pulses are sent directly into the brain to cause a seizure. ECT is used to treat severe depression and mania, and is considered a form of torture by many Mental Health Service Survivors

340

Section 7: The Future of the Union

For Lenin's version of this argument, see his [Declaration of the Editorial Board of Iskra \(1900\)](#)

341

See Vic Finkelstein's [Modelling Disability \(1996\)](#)

342

See Vic Finkelstein's [Outside 'Inside Out' \(1996\)](#) & [The Socail Model of Disability Repossessed \(2001\)](#)

343

First published in UPIAS's **Internal Circular: 24** (August 1978)

344

Several UPIAS members had proposed a special conference to discuss the crisis in the organisation, which eventually took place in Derbyshire in the winter of 1978

345

Finkelstein had been nominated by several UPIAS members for the General Secretary position ahead of Executive Committee elections in 1976. Finkelstein turned down the nomination and volunteered instead to be the editor of the Internal Circulars (which wasn't an elected position). Up to that point, editing the Circular had been largely a technical job – putting things sent by members or committees in the same document, producing enough copies and sending them – but Finkelstein argued that the editor needed to take a much more hands-on role. Finkelstein claimed that this should be a position in its own right, and couldn't be combined with another job on the Executive Committee.

346

First published in UPIAS's **Internal Circular: 27** (January 1979)

347

A piece called 'Union of the Physically Impaired' in UPIAS's **Internal Circular: 26(b)** (October 1978)

348

A quote from Finkelstein's article in Circular 20

349

This probably refers to the research work Finkelstein had been involved with while working for the Open University

350

Member G, though sharing Hunt's conclusions, questioned how useful the **Policy** was while it remained unclear on whether disability was an accidental by-product of how society was run or whether some people in power actively planned to keep physically impaired people remained segregated

351

From Finkelstein's 'Contribution to the Discussion on the Nature of Our Organisation' (1973, month of publication unknown).

352

Finkelstein's article 'Union of the Physically Impaired' accuses Hunt of being "deadly silent" on whether he believes society has changed in any way to make an organisation like the Union no longer workable or necessary

353

First published in UPIAS's **Internal Circular: 29** (June 1979)

354

Vic Finkelstein 'Back to Basics' in UPIAS's **Internal Circular: 28** (February 1979)

355

See **Reply to Vic Finkelstein** in this volume

356

From Finkelstein's 'Union of the Physically Impaired'

357

See **Correspondence with Christopher Foxley-Norris** in this volume

358

A dialectical relationship, in the sense Hunt is using the term, is one where two distinct entities (here society and people's beliefs) influence each other rather than one causing the other

359

From Finkelstein's letter declining to take part in the elections for UPIAS's General Secretary position

360

Alongside his article against Hunt's position in **Circular: 29**, Finkelstein wrote a short list of suggestions for increasing the Union's activity and the engagement of its members: including speeding up the production of an open newsletter, putting together an information pack on disability and oppression for teachers, and putting out a press release supporting striking workers in residential institutions.

361

First published in UPIAS's **Internal Circular: 29** (June 1979)

362

See **The Future of Our Union** in this volume

363

See **Reply to Vic Finkelstein** in this volume

364

See **The Future of Our Union** in this volume

365

A quote from Member H's article in **Circular: 26**

366

The Royal Association for Disability and Rehabilitation – the national umbrella organisation of medical, professional, and patient groups involved in rehabilitation services in Britain

367

The government supported charity responsible for providing adapted cars to people with mobility impairments

368

All the editions of Goldsmith's **Designing for the Disabled** that Hunt would have had

access to are out of print, and this quote does not appear in the heavily revised 1997 edition

369

Fundamental Principles of Disability (p.14)

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Hunt is referring here to the Alternative Corporate Plan (often referred to as the 'Lucas Plan') developed by trade unionists in the weapons industry. During the 1960s and '70s, Labour and Conservative governments alike promoted mergers between large firms making military equipment for both economic and military-strategic reasons (the fewer firms the government was dealing with, the easier it was to make sure they weren't selling weapons to rival nations). As with all mergers, this threatened the jobs of large swathes of the workforce. Facing the risk of severe job losses, trade unions across several threatened firms began a shop floor research project to look at the inventory, skill-sets, and equipment in each factory in the sector, and asked workers what they thought the factories could make if they no longer serviced weapons orders. Over 150 ideas were submitted, including kidney dialysis machines (as Hunt notes), wind-turbines, trams, hybrid car engines, and central heating systems for social housing. For an overview of the Plan see Dave King's 2019 article [The Lucas Plan: an idea whose time has come?](#) In **Science for the People** (Vol: 22; Issue: 2)