

## Care Homes, Covid-19 and Independent Living

While the official figures of deaths in the UK from Covid-19 have focused on deaths in hospitals, there is evidence that the true death toll is far higher, with potentially as many deaths again happening in care homes and other institutional settings. [More than a third of care homes in England](#) had recorded Covid-19 outbreaks by 15th May, while [29% of the deaths from Covid-19 in Greater Manchester](#) by that date happened in care homes. It has been estimated that [more than half of the deaths from Covid19 in England will have been connected to care homes by the end of June.](#)

The deaths in care homes that have been recorded are primarily those of elderly people, many of whom have dementia. It is not known, and [has possibly not even been recorded](#), how many people have died of Covid-19 in other categories of institutions, such as psychiatric hospitals and "assessment and treatment units" (ATUs), which largely contain people with learning difficulties and/or autism. [Activists including Simone Aspis are attempting to use legal action to force the Care Quality Commission \(CQC\) to release this information](#), but have so far not obtained definitive figures. This mirrors the frequently exclusive focus on older people in conversations about "social care", with both politicians and journalists often ignoring the fact that younger disabled people even exist.

The way that people in care homes and other institutions have been treated during this pandemic clearly shows that the government views them as disposable. Care homes have been used as dumping grounds for Covid-19 patients who have recovered enough that they are regarded as needing to leave hospital to make room for new admissions, but who are still not well enough to go home without ongoing medical care and/or other forms of support. Many if not most of these patients are still infectious. Moving them out of hospitals and into care homes therefore results in the Covid-19 virus spreading rapidly through those care homes, infecting long-term residents and staff alike. [ITV News has recently revealed that this was a deliberate policy.](#) The government also [rejected a plan put forward by public health officials](#) to lock down care homes to prevent deaths.

There have also been [several cases of blanket 'Do Not Resuscitate' \(DNR\) orders being placed on care home residents](#), including younger disabled people with learning difficulties. Many care homes have completely banned visits by family members in response to the virus risk, meaning that care

home residents are likely to die alone, and abuse and neglect are likely to go unmonitored.

Care home staff have also been infected with, and died from, Covid-19 at higher rates than any other occupational categories; indeed, [their death rate has been twice that of medical staff in hospitals](#). This may well be because, in comparison to hospital staff, care home staff have had much less access to adequate personal protective equipment (PPE), such as face masks. This may also have contributed to the [disproportionate impact of Covid-19 on black and other ethnic minority communities](#), due to the fact that BAME people are highly concentrated in the “social care” workforce. [As recently reported](#), black and Asian care home residents have also died of Covid-19 at higher rates than white care home residents.

In response to all this, there have been many calls for reform of care homes in order to make them safer. Greater Manchester mayor Andy Burnham, for example, has called for care homes and other ‘social care’ services currently run by private companies to be [nationalised and incorporated into the NHS](#). There have also been “feel-good” news stories such as that of a [Sheffield care home whose staff moved into the home](#) in March in order to prevent the spread of Covid-19 among the residents, portraying care home staff as heroic and selflessly dedicated.

In the immediate term, care homes undeniably have a desperate need for better PPE, staff training and many other resources. However, looking at the bigger picture, the Disabled People's Movement has always advocated not for the reform, but for the abolition of all segregated institutions. Indeed, in the UK the starting point of our movement was arguably [a group of disabled people trying to get out of a Leonard Cheshire care home in Hampshire](#). These struggles led to the development of the concept of Independent Living. This is based on the principles, as defined by Jenny Morris:

- that all human life is of value;
- that anyone, whatever their impairment, is capable of exerting choices;
- that people who are disabled by society’s reaction to physical, intellectual and sensory impairment and to emotional distress have the right to assert control over their lives;
- that disabled people have the right to participate fully in society.

Independent Living does not mean living alone or living without support - it means having choice and control over what support you get, who gives you it, when and how. One way that the Disabled People's Movement has campaigned for disabled people to get choice and control over the support they need is giving people money (direct payments) to employ their own personal assistants (PAs). This is one of the [Seven Needs for Independent Living](#) identified by Derbyshire CIL in the 1980s. PAs are different from the staff in care homes because the disabled person is the PA's boss and has control over what assistance their PA gives them and how. They are not acting out of charity or heroism, but simply doing their job.

[As reported by John Pring of Disability News Service](#), there is evidence that disabled people who use direct payments to employ PAs have been safer than people in care homes, despite the fact that many have been struggling to get councils to provide them with adequate personal protective equipment (PPE), such as masks and disposable gloves, for their PAs. [Research has shown](#) that people who work directly for disabled people as PAs find their work more enjoyable and less stressful than staff who work in care homes. It is very likely that directly employed PAs are also at a much lower risk of catching Covid-19 (or any other infectious diseases) than care home staff.

Directly employing PAs may not be suitable for every disabled person, and people with different types of impairments (for example those with learning difficulties or mental health needs) may need or prefer to receive different types of support, and may need more or less help with managing their support, but with the right support, and enough funding, it is possible for all disabled people to live in their own homes (whether alone or with friends, partners or families) in the community, have choice and control over their assistance, and have the same rights and freedoms as non-disabled people.

This includes the older people with dementia and other age-related conditions who make up much of the population of care homes, despite the fact that often they are not thought of as "disabled people". Disabled people's organisations should reach out to people in care homes to demonstrate that other ways of living with support needs are possible, whether someone has acquired support needs in older age or had them for their whole life. The right to independent living for all disabled people is protected by [Article 19 of the UN Convention on the Rights of Persons with Disabilities \(CRPD\)](#).

There are many ways to achieve independent living. Some disabled people would prefer to live alone and employ their own PAs, while others might enjoy living with other disabled people in a larger house and employing PAs or paying for other kinds of support collectively. The difference between a set-up like this and a "care home" would be that the disabled people are actively choosing to live together and have control over their support needs, rather than being placed in a care home against their own wishes and having when and how their support needs are met controlled by the care home management.

Independent living for all disabled people currently living in care homes may seem like a hugely ambitious goal, to the extent that some might view it as impossible. It would certainly require large-scale investment of money and other resources, and could not happen instantly. Councils and other housing providers would need to build much more accessible and affordable housing, and the government would need to fund (whether through local authorities or [a new national funding system](#)) a huge increase in direct payments to disabled people to employ PAs, as well as funding DPOs to provide support with recruitment and management of PAs.

However, we are already in a time of unprecedented change. [Some care homes are already being forced to close by the impact of the Covid-19 pandemic](#), and [directors of social services are worried about the sustainability of the private companies they have contracts with](#). However long the pandemic lasts, huge government intervention is going to be necessary for the UK to achieve social and economic recovery. There is no real reason, other than political will, why this intervention could not include guaranteeing a right to independent living for all disabled people and providing all the resources necessary to ensure that no disabled person is forced to live in a care home or any other segregated institution, and that every disabled person has choice and control over how their support needs are met.