

## Written evidence from Shared Lives Plus (COV0202)

# About Shared Lives Plus

Shared Lives Plus promotes **supportive shared living** through Shared Lives care and Homeshare with local and national governments. Our members are 6,000 Shared Lives carers, 150 Shared Lives schemes and over 20 local Homeshare organisations. We offer guidance, best practice, legal advice and insurance.

Around the UK, 10,000 **Shared Lives** carers open their homes to someone who needs support after hospital treatment, for mental ill health, dementia, learning disability, older age or for young people leaving care. Shared Lives care is composed of long-term arrangements, as well as day services, weekly visits and respite care. Shared Lives is consistently rated the best quality and safest form of care in England.

In **Homeshare** someone looking for companionship at home is matched with someone looking for affordable accommodation, tackling loneliness and housing issues in one solution. In a Homeshare the 'Householder' offers a 'Homesharer' a room in their home. In many cases, the Householder is an older person, whilst the Homesharer is a younger person.

## A human rights lens

This response to evidence outlines how people living in Shared Lives and Homeshare have been disproportionately affected by the curtailing of certain human rights during the government response to Covid-19. A lesson that has already emerged is that government policy and legislation should be formed through a lens of human rights. Human rights should not be tacked onto guidelines and policies after they have already been written and published. During the pandemic and its easing, the government must be guided by human rights laws to ensure that any legislation is proportional, necessary, lawful and time limited.

## People living in Shared Lives and Homeshare, Covid-19 and human rights

Shared Lives has a rich history of supporting people with a learning disability and autism, and the majority of people living in Shared Lives arrangements have a disability of some

kind. Shared Lives also supports older adults with a support need, and has proven to be a holistic, humane and reliable way of supporting people with mental ill health. The majority of Householders living in [Homeshares](#) are older adults, some with dementia. There are also a number of Householders who experience mental ill health or have a disability.

## Care Act easements

In theory, the [Care Act easements in England](#) allowed local authorities to relax some responsibilities in order to prioritise whilst under pressure, as long as they did not breach a person's human rights.

Shared Lives Plus shared the concern of other organisations supporting older adults and people with disabilities and autism about what this would mean in practice. Existing case law suggested that the threshold for finding a breach of a person's human rights was likely to be very high. This policy was also dependent on local authority workers understanding and applying human rights standards to individual cases. Whilst the easements used the rhetoric of human rights, they fell short of actually protecting the rights of older adults, and people with disabilities and autism.

## Right to life

Article 2 of the [Human Rights Act](#) (HRA) protects the right to life. For people in Shared Lives and Homeshare, this right has been eroded by some government policies and actions during the pandemic response.

## PPE

PPE has been a central element in combatting the spread of Covid-19. Between mid-March and the beginning of April, Shared Lives schemes reported significant difficulties in obtaining PPE. Problems included being told by the National Supply Disruption line they weren't on the list of recipients for PPE. By late March, one Shared Lives manager reported that, "We haven't even had a first delivery yet. I have been chasing for best part of last week and this has now been escalated to the complex case team as apparently they have no record of our service on their delivery list."

## DNRs and NICE guidelines

At the beginning of April, Shared Lives Plus became aware through news reports and conversations with Shared Lives schemes that a number of older adults and people with

learning disabilities across England were being issues with DNRs without any consultation. According to the [British Institute of Human Rights \(BIHR\)](#) the decision to issue a DNR to an older adult or person with a disability is not a medical decision, but discrimination. Shared Lives Plus welcomed the actions of the Care Quality Commission (CQC) who [issued a statement](#) condemning this practice.

Similarly, Shared Lives Plus was disappointed by the National Institute for Clinical Excellence guidelines which encouraged NHS staff to assess patients with autism, learning disabilities, and other conditions as [scoring high for frailty](#). Despite the later clarification regarding groups included in the Clinical Frailty Score, this incident is evidence of discrimination against certain groups and a lack of consideration for their human rights (Article 14 HRA).

## **Respect for a person's private and family life**

The right for respect of a person's private and family life as enshrined in Article 8 of the HRA includes being able to;

- develop a person's identity,
- forge relationships,
- participate in essential economic, social, cultural and leisure activities.

Government policy during the lockdown has demonstrated a lack of rights-based thinking about people with disabilities, older adults, and those with mental ill health.

### **Stay home**

At the beginning of lockdown, the government issued a "stay home" order. Consequently, some families of people living in long term Shared Lives arrangements refused to return their loved one to their Shared Lives carer. In a number of cases, the person supported by Shared Lives was not asked by their family or social worker where they wanted to be, violating their Article 8 rights. Greater government emphasis was needed on the presumption of capacity and the need to consult people with disabilities and autism, and older adults during the pandemic response.

### **Rules about going outside**

Another example of how a lack of rights-based thinking impacted those in Shared Lives were the initial rules restricting people to exercise once a day, near to their home. Many people with disabilities and mental ill health in Shared Lives struggled with these

restrictions. Shared Lives carers reported that for some people they supported the restrictions had resulted in severe anxiety, increased self-harming, problems sleeping and destructive behaviours.

- One Shared Lives carer reported that without being able to go out more than once a day, the person they support struggled to follow a routine. This caused a change sleeping patterns, with the person “staying up late or sleeping in later in the day and become a bit withdrawn or argumentative at times, usually due to being tired”

The once a day rule was challenged and amended so that people with learning disabilities or autism could leave their home up to three times a day out of area. A number of Shared Lives carers reported an improvement in the emotional wellbeing of the people they supported.

- A Shared Lives carer reported that the changes to the rules were positively benefiting the person they support “requires familiar open space with no other people too close, [which] involves a necessary drive in the car.”

## Face coverings

The [Health Protection \(Coronavirus, Wearing of Face Coverings on Public Transport\) \(England\) Regulations 2020](#) require people aged 11 and above to wear a “face covering” when using public transport unless they have a “reasonable excuse.” Regulation 4 provides a non-exhaustive list of what counts as a “reasonable excuse.” Shared Lives Plus welcomes these exceptions. However, it is clear that the Government expects operators of public transport to use their own judgement of what is meant by “severe distress,” And to effectively make decisions for which they have may not been trained. This again highlights the disproportionate impact of government policies for some people with disabilities and autism.

## Looking forward

Future action is required to ensure that those most at risk of having their human rights curtailed in the event of a public health emergency are protected. Government and public health officials should take concrete steps to explicitly include people with disabilities, older people and those with mental ill health in emergency planning and health response. This means;

- Identifying and removing any barriers to treatment. This includes;

- Accessible environments
  - Available/ understandable health information
- Provision of treatment should not be made on the basis of disability or chronological age;
  - Neither age nor disability should not be used as criteria for determining people's vulnerabilities, prognosis, or treatment
- Age and disability should also not be used for the allocation of goods and services, such as PPE
- Health/ local authority workers should be given awareness-raising training to prevent discrimination based on prejudice against older adults, people with mental ill health and people with disabilities.
- It is essential that decision makers consult with and engage with older adults, people with disabilities and people with mental ill health as well as their representative organisations. A rights-based response to a public health crisis such as a pandemic should include and respond to those who will be most adversely affected

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