

# Scottish Independent Living Coalition (SILC) of Disabled People's Organisations<sup>1</sup>

## Call for immediate action: Disabled people's human rights to life and health under threat

### Our human rights

**It could not be clearer.** Disabled people have human rights to life and health<sup>2</sup>. We have rights to the 'highest attainable standard of health without discrimination on the basis of disability'<sup>3</sup>. Governments must 'prevent discriminatory denial of our health care or health services or food and fluids on the basis of disability' and take steps towards ensuring 'the creation of conditions which would assure (access) to all medical service and medical attention in the event of sickness'<sup>4 5</sup>.

Human rights do not cease to apply in times of crisis. They become more important. Human rights oblige Governments to take 'all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters'<sup>6</sup>.

Research shows that disabled people, which includes people with long-term health conditions, sensory impairments, learning disabilities, HIV and cancer for example, have fewer resources to support themselves through an emergency situation. This includes disabled people of all ages living in care homes as well as those living in the community. According to research we are also disproportionately affected, under-considered and under-served by official responses in times of emergency<sup>7</sup>.

Even before the COVID-19 pandemic, the support services necessary for us to fulfil our human rights and make our full contributions to society were often lacking. Too often people treat us as second-class citizens, even as a burden on society. This pandemic has shone a spotlight on the lack of resources in

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<sup>1</sup> Organisations led by disabled people. <https://inclusionscotland.org/wp-content/uploads/2018/10/DPO-directory-2018.pdf>

<sup>2</sup> Article 2, Human Rights Act; also Article 3 Universal Declaration on Human Rights and Article 10 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

<sup>3</sup> Article 25 UNCRPD

<sup>4</sup> Article 12 International Covenant on Economic, Social and Cultural Rights

<sup>5</sup> These rights are carried forward in Scotland in the Scotland Act and through the Patient Rights (Scotland Act) and are described in The Charter of Patient Rights and Responsibilities

<sup>6</sup> Article 11 UNCRPD

<sup>7</sup> <https://ncd.gov/publications/2006/Aug072006>

the NHS and the long-term chronic underfunding of the social care sector<sup>8</sup>, as demands on both have suddenly and massively increased.

## **Under threat**

The consequences of all these combined is clearly apparent in the alarming evidence we have been receiving of the impact on disabled people's lives and human rights. Disabled people and family carers are feeling pressured into agreeing to Do Not Resuscitate notices, or to not being admitted to hospital if they fall ill. Their expressed wishes are not always being respected. They are being refused equal access to life-saving treatments, not obviously on grounds of health status but because they are disabled people, although ill-health and disability are not necessarily related. There is talk of 'frailty scales', used to score who should have access to treatment, which quite wrongly appear to equate social and personal care support needs with health status. Disabled people are seeing the care packages they very much depend on withdrawn overnight. Directly employed Personal Assistants and family carers cannot get access to the Personal Protective Equipment they need to be safe. Many disabled people at great risk are not on the 'shielding' list and so cannot access associated support. The result of all this will be to increase demand on acute healthcare services.

We know that there just are not enough resources to meet all demands, or to meet them straight away. We know impossibly difficult decisions may need to be made about who receives what health care and ultimately who lives and who dies. We know the Cabinet Secretary has stated that "No one's life in Scotland is worth more or less than anyone else's". We know that what is happening on the ground is not necessarily a reflection of policy intention.

We know that there have been Scottish Government announcements of actions that aim to address issues of the kind described. But, what is happening in the cases we are hearing, tells us that these are not reaching disabled people on the ground, or not meeting disabled people's needs and concerns. Meanwhile, disabled people are experiencing breaches to their human rights and discrimination. **This cannot be allowed to continue.**

## **Call for immediate action**

The Scottish Independent Living Coalition is calling on Scottish Government and leading clinicians to take immediate action to put this right, and to offer our assistance.

- 1. No one must be or feel pressured into agreeing to a Do Not Resuscitate (DNR) notice, or to not being admitted to hospital if they**

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<sup>8</sup> <http://www.sdsscotland.org.uk/wp-content/uploads/2016/07/Shared-Ambition-for-social-care-final.pdf>

**get ill, and their expressed wishes must be respected.** Of course, people may wish to exercise choice and control over what happens, should they be approaching the end of their lives. If so, they need information and their wishes must be respected. Decisions should never be made without our consent and we should be supported to make decisions if we need it. The First Minister and Chief Medical Officer<sup>9</sup> have publicly been very clear on these points. Disabled people and carers, clinicians and GPs need to be aware what the policy is and ensure that it happens. The planned guidelines on anticipatory care planning (Health Improvement Scotland) should also make this clear<sup>10</sup>.

2. **A fast-response service should be set up through which concerns and complaints can be raised and rapidly addressed.** These could be about healthcare, anticipatory health planning, care homes and availability of personal protection equipment (PPE). This obviously needs to be fully accessible to disabled people, their families and carers, and others who may be affected, so they can raise concerns about access to health care and DNR notices in particular. Issues arising through the service should then be monitored and publicly reported on.
3. **Decisions about an individual's access to healthcare must be based only on expected health outcomes, not on disability status or use of social care or other support.** Disability may affect *how* healthcare will be delivered to make it accessible, but not *if* it is delivered. Frailty scales or similar methods for decision-making and professional Codes of Practice need to make this clear. Scottish Ministers, leading clinicians and professional bodies must clearly and publicly direct those working in the NHS to correctly apply the national policies that explicitly say 'A medical DNACPR decision should be based on the clinical judgement that effective CPR will fail in achieving sustainable breathing and circulation...rather than any judgement about the quality of life that may be achieved.'<sup>11</sup> For example, learning disabled people currently have life expectancy 20 years lower than others, for many reasons, and this in itself should never be a reason to withhold healthcare.
4. **Disabled people who live in residential care homes and those who employ Personal Assistants (PAs) or who rely on family carers must have access to Personal Protection Equipment (PPE) and other support they need.** The needs of PA employers and unpaid family carers have recently received some attention but they still need to be given much greater priority. They need PPE to be safe. They may need advice. They may need urgent back-up support should they fall ill. The same goes for staff in residential care homes looking after disabled people of all ages.

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<sup>9</sup> <https://www.eveningexpress.co.uk/news/scotland/no-one-should-be-pushed-into-signing-do-not-resuscitate-order-says-sturgeon/>

<sup>10</sup> <https://ihub.scot/project-toolkits/anticipatory-care-planning-toolkit/anticipatory-care-planning-toolkit/>

<sup>11</sup> <https://www.gov.scot/publications/attempt-cardiopulmonary-resuscitation-dnacpr-integrated-adult-policy-decision-making-communication/pages/4/>

5. **No disabled person who needs it should have their existing care package withdrawn.** Scottish Ministers should work with providers to ensure that disabled people get the social care support they need at this time. There should be no reduction or removal of social care support packages. When carers cannot attend e.g. because they are ill, suitable alternative care should be provided. Disabled people who employ their own PAs or carers, and disabled people who are carers, should also be considered in this. Service providers should make sure that disabled people can contact them with ease and that information about this is widely available.
6. **Scottish Ministers should review the 'Shielding List' and the support it offers.** This currently only includes people with certain clinical needs. It does not cover many disabled people who need to shield but who are not on the clinical list. We know that some disabled people are struggling to get included on the list and are therefore missing out on the support that is available. The nature of this support also needs to be reviewed to make sure it consists of what people actually need, e.g. so that people can access priority online shopping and a wider choice of 'basic boxes'.
7. **More should be done to improve communications and the quality of information provision, ensuring accessibility.** Disabled people need full and timely information about what to expect, what their rights are and who can help them challenge decisions. Many disabled people are isolated. Some will have communications barriers e.g. BSL should be provided as a duty within healthcare settings. It is important they are reached. Third sector organisations may have a role to play in enabling this.
8. **Monitoring of what is happening on the ground is imperative.** To identify what is happening on the ground right now, to ensure policies, guidance and Codes of Practice are having the impact desired and to plan for the future, monitoring will be essential. For example, this might include information received by third sector organisations, data segmented by geographical area, and protected characteristics. The finding of such monitoring should be publicly reported.
9. **Learning must be used to ensure more resilient services and support are in place for the future.** There will no doubt be a great deal to learn from the challenges of responding to the pandemic, not least in view of a starting point where social care support services were already in very poor shape. Learning could enable more robust systems and support services for disabled people to be established for the future. Such learning must not be wasted.
10. **Disabled People's Organisations (DPOs) are led by disabled people themselves and should be involved in developing the actions.** It is vital that all the actions listed are fully informed by the lived experience of disabled people. Without this, central decision-makers may

not know what is actually happening on the ground, whether policy intentions are being met, whether guidance is being followed and whether it was the right policy and guidance to achieve the desired impact in the first place. The organisations that make up the Scottish Independent Living Coalition are well-placed to access that information. We would welcome opportunities to ensure disabled people's voices are heard and our human right are fully met.

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This Statement is supported by Members of the Scottish Independent Living Coalition



