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22 April 2020

## **COVID 19 AND THE RIGHTS OF DISABLED PEOPLE**

Dear Minister Swann, Dr McBride and Mr Holland;

I would like to start by thanking you, your Departmental colleagues and all our health care professionals for the considerable efforts and sacrifices that are being made to protect us all during this global Pandemic. As an organisation we fully recognise the scale of the current challenge and what lies ahead.

I write to you as a matter of urgency in this open letter to seek reassurance and clarity for our community here in NI. Disability Action have been working with and contacted by many disabled people and their families who are understandably very worried by UK Wide emergency legislation and medical guidance. We are also now aware of growing local media reporting in respect of treatment issues for disabled people during this time.

We share with you a statement below which has been developed with Disability Organisations UK wide. It has now been publicly endorsed by Professor Stephen Powis, (National Medical Director, NHS England and NHS Improvement) and Ruth May, (Chief Nursing Officer, NHS England and NHS Improvement). It has also influenced the development and publication of the Welsh Government's 'Coronavirus: ethical values and principles for healthcare delivery framework'.

'The NHS is built on the principle that we are each equal in dignity and worth. It expresses our commitment to protect one another's right to life and to health, no matter who we are.

Disability Action (NI), Portside Business Park, 189 Airport Road West, Belfast, BT3 9ED.

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We recognise that the NHS faces unprecedented pressures. We know that its staff will have to make difficult decisions about who gets treatment and care and who doesn't. We understand that they will have to judge whether people will benefit and we know that people's existing health will be taken into account.

However, we have read about cases that have made us feel worried that the principles on which the NHS are built are sometimes not being upheld. We are deeply concerned that the rights of disabled people, of all ages, as set out in the Human Rights Act (1998), the Mental Capacity Act (NI) (2016), the Disability Discrimination Act (2005) and the United Nations Convention on the Rights of Persons with Disabilities (2006) and the Convention on the Rights of the Child (1989) are not always being upheld. NHS staff normally use these laws to help make decisions about people's treatment. In this crisis it's more important than ever that all NHS staff follow them.

To ensure that this happens, we believe that it is critical that **everyone involved** is guided by the **following principles**:

- Our individual chance of benefiting from treatment should we have
   Covid-19 must not be influenced by how our lives are valued by society.
- Where we have existing health conditions or impairments that are unrelated to our chance of benefiting from treatment, they must not play any part in decision-making regarding our equal right to access such treatment.
- The fact that we might have significant levels of social care and support needs, or that we may do so in future as a result of the pandemic, should not make health staff think that we will not benefit from treatment.
- We have the right to be fully involved in decisions about our own lives, including life and death decisions. Decisions should never be made without our involvement, or consideration of our best interests. There is

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no justification for policies based on age or learning disability that do not treat each of us with respect and as individuals.

- We all, and our advocates, have the right to know about decisions that may be made about us that will affect us.
- Guidelines on the assessment, provision, and evaluation of treatment and care provided to individuals during the Covid-19 pandemic must be developed in collaboration with disabled people's organisations and representatives from human rights bodies.

We cherish the NHS and the values that it represents. We stand ready to do whatever we can to support it to stay true to its founding principles in the difficult days, weeks and months ahead.'

In the current absence of a standalone Northern Ireland Specific ethical framework for treatment of Disabled People during Covid-19, we respectfully call upon you all as a matter of urgency, to now clearly and publicly endorse the principles as laid out above.

We look forward to hearing from you.

Yours Sincerely

Andrea Brown Chief Executive (Interim), Disability Action

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