

## **Written evidence from Neurodivergent Labour (COV0097)**

Neurodivergent Labour is an organisation of dyspraxic, dyslexic, autistic and otherwise neurodivergent members and supporters of the Labour Party. Our submission to this call for evidence on the human rights implications of the government's response to the Covid-19 crisis outlines our concerns about issues such as reduction in social care and education provision, social distancing rules and their implementation, workers' rights, and deprioritisation of some categories of people for medical care.

Neurodivergent Labour joins other disabled people's organisations in objecting to the sweeping new powers that the government has given itself and the potential impact this will have on our rights and our lives.

The measures in the Coronavirus Act limit the rights of children and young people with Special Educational Needs and Disabilities (SEND), remove councils' duty to provide social care and restrict the rights of people in mental distress.

We have been contacted by neurodivergent people who are finding the current situation very distressing, and who have little faith in the authorities to assist them.

References cited are to Articles of the Human Rights Act except where otherwise specified.

### **The right to social care**

(Article 2: Right to life; Article 8: Respect for your private and family life, home and correspondence)

The Coronavirus Act removed councils' duty to provide social care. Several councils have now used their 'easement' powers under the Act to withdraw crucial services to people who need them, impacting negatively on their human rights.

During the pandemic, many autistic and other neurodivergent people are not getting the number and duration of home visits that they are entitled to.

Moreover, many neurodivergent people have co-occurring conditions, and may have complex care needs.

While social care is reduced, many neurodivergent people's care needs have increased. Cancellation of daily activities - whether it is school, college, work, volunteering or day care - has impacted negatively on neurodivergent people's wellbeing. Unpaid carers such as family members must be allowed to take paid special leave from their jobs in order to provide care.

An autistic adult who cares for his mother told us that "I have no priority treatment with the local authority or when getting shopping for mum. It has been hard to cope without the necessary community support. Even before the outbreak my emotional needs were not met most of the time. Being a carer for mum means if I could not assist mum, then she could suffer too."

## **Care homes**

(Article 2: Right to life; Article 8: Respect for your private and family life, home and correspondence)

It is acknowledged now that there is an epidemic of the virus in care homes. This comes against a background of three decades of cuts and privatisation in the sector, which have left many care homes underfunded, unaccountable and staffed by underpaid, insecure workers.

There have been repeated scandals exposing abuse and neglect in care homes. A year ago, it was revealed that forty autistic and/or learning-disabled people had died in care in a period of just three years.

This has made care homes very vulnerable to a virus such as this, and we are now seeing thousands of unnecessary deaths.

The National Health Service and social care must get the resources they need, with privatisation ended and the pharmaceutical industry brought into public ownership

## **Resuscitation and death**

(Article 2: Right to life)

Autistic and other neurodivergent people have the right to live, and the right to appropriate medical care.

There have been repeated reports of GP surgeries and other bodies trying to have 'Do Not Resuscitate' DNR orders issued to autistic people. This contradicts NICE advice, although the fact that NICE had to amend its original advice to make this clear may well have contributed to this deplorable situation.

A disabled mother of an autistic child told us: "My daughter if she catches Covid 19 (or I for that matter) could be refused treatment and care, and be classified as lowest priority for lifesaving treatment with the possibility of a DNR being put on her notes unbeknown to us! This is extremely concerning to us. Everybody should have the same right to life. This type of discrimination reminds me very much of the dark appalling world of Eugenics and this scares me greatly!"

The Coronavirus Act relaxes the requirement for notification and investigation of death, reducing the rights of people to have their loved ones' deaths explained, and to identify contributory factors.

## **Social distancing measures**

(Article 5: Right to liberty and security; Article 8: Respect for your private and family life, home and correspondence)

Many autistic and some other neurodivergent people rely on routines and visits to familiar places. While some of these places are closed during lockdown, they must

be allowed to visit others (eg. parks) within social distancing rules. This may involve going out more than once per day.

Clarification was eventually given that this would be allowed, but by this time, many autistic people had been distressed by worry and/or excessive policing.

## **Special Educational Needs and Disabilities (SEND)**

(Protocol 1, Article 2: Right to education)

The Coronavirus Act reduces the right of SEND children to education that meets their needs.

Although public health considerations meant that serious changes were required to how education is provided, this does not require children with special needs to have their legal right to education curtailed.

A mother of an autistic child told us that her local Children's Continence Service has been withdrawn due to the Covid-19 situation, leaving her having to spend more than £150 a month on incontinence nappies for her daughter.

## **People in mental distress**

(Article 3: Freedom from torture and inhuman or degrading treatment; Article 5: Right to liberty and security; Article 7: No punishment without law)

The Coronavirus Act restricts the rights of people in mental distress, by reducing the requirement for two doctors to authorise a person to be forcibly detained ('sectioned') to just one doctor.

Given that firstly, autistic and other neurodivergent people are more likely to experience mental distress, and secondly, that neurodivergent behaviours are often inaccurately seen as evidence of mental distress, this is a threat to the human rights of neurodivergent people.

People experiencing mental distress need support not incarceration.

## **Neurodivergent workers' rights**

(Article 4: Freedom from slavery and forced labour)

All workers (including neurodivergent people and those who work alongside us) must be allowed to follow government guidelines eg. staying away from work, without loss of pay or threat of discipline. Inadequate pay for those sick, isolating or furloughed breach this, and coerce people into attending work when this is a danger to themselves and others.

An autistic person told us that, "I have been furloughed by work. My current income from work is just under three hundred pounds a month. I am not eligible for Universal Credit, so am having to claim Carer's Allowance due to my mum having caring

needs. Without the Carer's Allowance and my PIP, being able to buy food would have been a problem.”

Moreover, work experience schemes for autistic people, such as TfL's Steps Into Work, have been suspended, with only a little activity and contact put in its place.

### **The right to health information**

(Article 8: Respect for your private and family life, home and correspondence; Article 10: Freedom of expression)

For neurodivergent people to understand public health advice, it needs to be communicated in various formats, to be jargon-free, and to be in dyslexia-friendly layout.

### **Involvement in decision-making**

(Article 4(3) of the UN Convention on the Rights of Persons with Disabilities)

To ensure that our rights are being upheld, we need the involvement of elected representatives of neurodivergent in scrutinising government policy and service provision.

*9/05/2020*