

The impact of the COVID-19 pandemic on equalities and human rights (<https://yourviews.parliament.scot/session-5/impact-covid-19-pandemic-equalities-human-rights/>)

Response 894069412

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☐ Include unanswered questions

About you

What is your name?

Name

Iain Smith

Are you responding as an individual or on behalf of an organisation?



Organisation

The impact of the COVID-19 pandemic on equalities and human rights

How have groups of people been affected by the virus?

Please enter your answer in the text box below

Inclusion Scotland is a Disabled People's Organisation (DPO) – led by disabled people ourselves. Inclusion Scotland works to achieve positive changes to policy and practice, so that we disabled people are fully included throughout all Scottish society as equal citizens.

The COVID-19 pandemic is impacting on all areas of our lives. In just a few weeks, life as we knew it has changed beyond recognition. Disabled people are not just at risk from the virus. We are at risk from the actions of public bodies and others who do not understand who we are, what we need or what will work. Why? Because they have not asked us. Not only will this mean that thousands of us do not get what we urgently need but getting it wrong costs providers valuable time and money. Yet, as disabled people, we are well used to finding solutions to do things because the usual ways do not work for us.

Which groups have been disproportionately affected by the virus and the response to it?

Please enter your answer in the text box below

Inclusion Scotland wants policy and decision-makers to know what is really happening to disabled people on the ground, and what changes are needed. To

find this out, we conducted a survey throughout April to hear from disabled people and those who support a disabled person, about what has happened to them since the start of COVID-19 changes. We have asked about issues and barriers they have faced, and about any positive experiences.

(The survey ran from 01-30 April 2020 and was widely promoted to our members and disabled people through social media, newsletters and by partner organisations, including the Scottish Human Rights Commission. A summary of initial findings can be found here: <https://inclusionscotland.org/COVID-19-evidence-survey/>)

Inclusion Scotland received over 800 responses to the survey from all parts of Scotland . This is in addition to the direct messages we receive every day from disabled people on Facebook, Twitter and email. Some of the key survey findings are set out below.

- Social Care Support

The provision of social care support, both formal and informal, has been seriously affected since the start of the crisis. Every day Inclusion Scotland is hearing of people having social care support packages cut, right when they most desperately need them. Almost half of those who answered this question in our survey (45%) said that the current COVID-19 crisis had impacted on the social care support that they receive. A further 12% of respondents said it may have an impact in the future. Around a third of respondents who answered this question said that the social care support that they received had either been stopped completely or had been limited.

Some disabled people have effectively been left bedbound by the loss of their social care support. Some respondents noted that they were now either acting as carers to family members, or are having to rely on family members to care for them. Although some people may have already provided care and support to their family member pre-COVID-19, the current situation is placing a greater strain on carers, some of whom are disabled people themselves. Loss of social care support has also put pressure on families if a person has had to move in with a carer due to loss of their usual support and is having a detrimental

impact on many disabled people's rights to independent living.

- Do Not Resuscitate Notices (DNR) and Access to Medical Treatment

Although we didn't ask a specific question about DNR, four respondents told us that they or someone they know had been asked to sign a DNR notice or informed that they would not be ventilated should they contract COVID-19.

People reported that their mental health was being impacted by the worry that they might be denied treatment because of their impairments.

Others spoke about their worries in relation to not being able to access medical appointments or routine health services, which have been cancelled as a result of the crisis. This includes mental health clinics and group therapy sessions, access to Child and Adult Mental Health Services and therapeutic services such as physiotherapy, occupational therapy hydrotherapy and therapeutic swimming.

- Caring for Children and Others

Around 40% of people who responded to the question on caring told us that they had experienced changes or challenges with caring for children or other family members at home since the start of the pandemic. A further 10% of respondents told us that they thought that they might experience changes or challenges in the future.

The most common theme identified was the impact of the loss of their services and provisions during the pandemic. Many parents spoke of their children losing vital services that would have been provided through the school and the additional strain of having to educate children at home. A number of comments refer to an increase in violent outbursts and self-harm from disabled children and young people due to disruptions to their routines and services being suspended.

Respondents also reported increased anxiety and poor mental health due to the increased strain of caring for children or family members at home during COVID-19.

- Access to Food and Medicines

Around two thirds of respondents to this question (64%) said that the current crisis has had an impact on getting the food and/or medicine that they need for themselves or the person that they support/care for. A further 16% of respondents said that getting access to food and medicine might be an issue for them in the future.

Respondents who considered themselves at high risk from COVID-19 reported difficulties in obtaining food or medicines. Some had no way of obtaining food or medicines unless they, or someone else at risk, went out to the shops/pharmacy. Many respondents have reported difficulties in accessing food and/or medicines because they are not prioritised for home deliveries by supermarkets, and when they do go shopping their impairments are not taken into account by supermarket staff. Some of those responding lived in rural areas where bus services have often been withdrawn, causing additional issues.

- Social Distancing and Isolation: Impact on Mental Health

Disabled people with and without pre-existing mental health conditions are finding everyday life under lockdown extremely stressful. Respondents to this question told us that they are anxious about their own health, the health of those that they care about and many are very fearful for the future. Some examples of what we have heard from disabled people or their carers about their current mental health are extremely concerning. Significant numbers of disabled people (15) with existing mental health problems have reported to us, via this anonymous survey, that they are feeling suicidal at this time.

Significant numbers of disabled people and those that support them are struggling or unable to abide by social distancing rules when in or out of the home. For example, because they themselves need personal care, or provide such to another disabled person.

Parents of young or adult children with additional support needs report very stressful experiences being in lockdown at home, particularly lone parents of one or more disabled children.

Individuals and families are struggling to take any form of exercise, when previously able to do so. This is causing stress and anxiety and worsening pre-existing mental health problems. It is also exacerbating chronic pain conditions when suitable forms of exercise (e.g. swimming) are no longer possible, and when therapy sessions are no longer available, again contributing to poor mental health and a potential mental health crisis.

- **Social Security and Benefits**

One in nine (11%) people who responded to this question have experienced a negative impact on their access to benefits because of the COVID-19 emergency. Around one fifth (17%) anticipate that they might face problems in the future. Many of those who reported that they had no problem with access stated that this was because they were already in receipt of benefits and therefore did not have to make a new claim at present.

The majority of those with access to benefit issues were Personal Independence Payment claimants or recipients. Their issues were either delays in assessing their initial entitlement or delays in carrying out a re-assessment.

Some people reported issues with accessing social security as they needed support in making a claim or completing forms but could not access it at present. Other respondents reported problems in cashing benefit payments because of the risks posed to their health in venturing out to the bank or post office.

- **Employment**

Around one in ten respondents to this question (11%) were concerned that they could lose their job in the future as a result of the pandemic. A proportion of people who said that they had not lost their job told us that they were either self-employed or contract workers, and had lost work as a result of the crisis.

Some respondents noted the challenge of working from home at the same time as having new or increased caring responsibilities, including home schooling children who normally have additional support in school and looking after

children or adults who normally have care support, either at home or in other settings.

Have there been specific equality or human rights impacts on groups of people as a response to the virus?

Please enter your answer in the text box below

Inclusion Scotland are concerned that the emergency measures to combat COVID-19, including the Coronavirus Act and the Coronavirus (Scotland) Act have not been subject to adequate Equality and Human Rights Impact Assessments. We have particular concerns regarding the failure by the UK and Scottish Governments to take account of the State Party's obligations under the United Nations Convention on the Rights of Disabled People (UNCRPD) , including:

- Article 10: Right to life: States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.
 - o Concerns over use of DNR and prioritisation of treatment for COVID-19 patients.
- Article 11: Situations of risk and humanitarian emergencies – States Parties shall 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.
 - o Too little account has been taken of the needs of disabled people in planning on how to deal with coronavirus, and disabled people or their representative organisations (DPOs) have not been included in the contingency planning processes.
- Article 12: Equal recognition before the law - that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and

tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body.

- o Changes to the Adults with Incapacity (Scotland) Act (AWIA) introduced by the Coronavirus (Scotland) Act (CSA) disapply the key principle of the AWIA that “account shall be taken of the present and past wishes and feelings of the adult so far as they can be ascertained” when assessing if they are in need of social services. This is a direct contravention of Article 12.

- o The CSA also “stops the clock” in relation to time limited guardianship orders, which contravenes the requirements that these should “apply for the shortest time possible” and to be “subject to regular review by a competent, independent and impartial authority or judicial body”.

- Article 14: Liberty and security of the person - if persons with disabilities are deprived of their liberty through any process, they are on an equal basis with others.

- o The Coronavirus Act allows extending the existing timescales for compulsory measures, such as detention or treatment orders, or reduce the safeguards that currently have to be met before these compulsory measures can be introduced, such as reports from a Mental Health Officer. There are already doubts as to whether the existing safeguards are sufficient to be compatible with Article 14.

- Article 17: Personal integrity of the individual - Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

- o The CSA “stops the clock” on medical treatment orders under the AWIA and may extend medical treatment that the adult has not consented to.

- Article 19: Living independently and being included in the community – (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

- (b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

- o Changes to social care support legislation allow local authorities to provide services without an assessment. This may result in a person being discharged from hospital to a care setting that they do not wish to go to (in breach of (19a)). This may also breach Article 14.
 - o Disabled people do not receive the social care support that they need to support independent living (in breach of 19(b)).
 - o Cuts in social care support packages are also affecting disabled people's rights to independent living.
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- Article 21: Freedom of expression and opinion, and access to information - Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost.
 - o Not all information and guidance on COVID-19 is being provided in accessible formats, such as subtitled audio communications, Easy Read, Braille or BSL, and disabled people are less likely to be able to access the internet than non-disabled people. For example, the deadline for people to submit their views online on the Framework for Decision Making closed before the Easy Read version of the document was produced. This has excluded some disabled people who are generally more marginalised and seldom heard, from taking part in the process.
 - o The Scottish Government, however, responded quickly to our request to have a BSL signer at the daily COVID-19 briefings, something the UK Government has to date failed to provide.
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- Article 25: Health - Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.
 - o Disabled people have been put under undue pressure to sign DNR forms and decisions on the prioritisation/deprioritisation of treatments are being based on a disabled person's impairment or underlying health issues.
 - o The loss of access to the usual health treatments undermines a disabled person's rights to health and wellbeing.

What do the Scottish Government and public authorities (e.g. local authorities, health boards etc.) need to change or improve as a matter of urgency?

Please enter your answer in the text box below

COVID-19 continues to impact disproportionately on disabled people and those with long- term conditions. Disabled people are seeing their hard fought for human rights, such as the right to Independent Living, undermined by measures to combat COVID-19, in particular as the needs of disabled people have not been fully considered in the planning or implementation of these measures.

Inclusion Scotland recognise that public authorities are trying to do their best in very difficult circumstances. However, despite good policy intentions, sometimes things are just not happening on the ground. Cuts to social care support packages, lack of access to food and medicines and denial of medical treatment are all significant concerns for disabled people. The impact on mental health of the continuing lockdown on disabled people and family carers need to be addressed. These are urgent issues that need to be rectified.

Inclusion Scotland recognises that extraordinary measures need to be taken by governments to address COVID-19 (coronavirus), and these will inevitably impact on the day to day lives of all citizens. However, in designing and implementing proportionate measures needed to address COVID-19, governments must also be mindful of the need to protect as far as possible the human rights of all its citizens.

In some cases, the emergency legislation is not proportionate by introducing blanket changes to existing protections that go beyond addressing the specific issues that may arise as a result of the COVID-19 crisis – particularly in relation to Mental Health, Social Care and Adults with Incapacity. These measures impact disproportionately on disabled people.

There is an urgent need to ensure that disabled people and Disabled People's

Organisations are included as equal partners with all levels of Government – UK, Devolved and Local – and public bodies, in the contingency planning for COVID-19. This includes planning for exiting lockdown in order to ensure the needs of those households who are under particular pressure due to social distancing rules are prioritised, and the longer term planning for rebuilding a much more inclusive society when we emerge from COVID-19.

What do the Scottish Government and public authorities need to change or improve in the medium to long term?

Please enter your answer in the text box below

Inclusion Scotland has published a Statement on our Core Asks of Scotland's policy and decision-makers, service providers, employers, retailers, academics, funders and to our broadcasters and wider society to involve and support disabled people during Covid-19 (This can be found at <https://inclusionscotland.org/covid-19-evidence-survey>):

1. Stop stigmatising disabled people as vulnerable and problematic
2. Promote, not diminish, our human rights as disabled people
3. Involve us, the experts in our own lives, both now and when we build the 'new normal'
4. Support our national and local disabled people's organisations so that we can be involved
5. Communicate with us and inform us in ways that are accessible to us

We urge the Equality and Human Rights Committee to endorse these asks.

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