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### 1. Introduction

Never again should disabled people be left behind during a national emergency and our rights to life, to social protections and to equal and active participation in our communities be eroded as they have been throughout this crisis.

The Covid-19 crisis hit hard and it hit quickly – and it hit disabled people most of all. As things stand this looks likely to continue.

It is not just the catastrophic impact of the virus itself that has caused so many problems for disabled people. Inaction, turmoil and the indifference to our lived experience and expertise all play a part in shutting off our rights and leaving us behind.

That is not to say that there has been no action at all. In Scotland, our Government and communities have been supportive but there is an abyss between the rhetoric of national policies and what happens on the ground. This is piled on top of decades of discrimination, exclusion and latterly austerity that disabled people contend with and which impacts on every part of our daily lives and future potential, and our capacity to deal with crisis. The evidence in our report highlights this.

The findings of Inclusion Scotland's Covid-19 survey are stark. Over 800 disabled people responded throughout April 2020 to share what they were living through. From losing vital social care support and being left unable to get out of bed, to fears about involuntary 'do not resuscitate' notices and job losses, people told us they were 'being pushed to the brink'. 15 people told us they felt suicidal.

We quickly issued a short initial findings report of our survey to expose the issues that disabled people were facing, bringing them to the attention of the officials and organisations who could do something about them and start listening to disabled people.

Rights At Risk is a more comprehensive look at our survey findings. It takes stock of the situation disabled people were in before the pandemic, what happened to disabled people during the first months of the crisis as emergency responses were rolled out, what the long-term impact of the crisis is likely to be for disabled people and what needs to happen now. We quote directly from the real-life examples that people shared with us.

The Covid-19 crisis is far from over, and while we recognise that some issues are being addressed, disabled people are still experiencing consequences that are likely to continue, and even worsen.

This report seeks to ensure that disabled people's voices are heard by national and local policy and decision makers and service providers who must learn the lessons from our experiences during the pandemic. This report will also be of interest to academics, other researchers and disabled people as an important record of disabled people's experiences during the pandemic.

## 1. At the beginning of the crisis

Disabled people's starting point at the beginning of the pandemic was not good. Prior to the lockdown, disabled people were already some of the most marginalised and excluded in society. For decades we have experienced worse outcomes than our non-disabled peers in many areas of life. We are more likely to live in poverty, more likely to earn

less than non-disabled people, less likely to leave school with qualifications and the list goes on (Scottish Government, 2019b).

Many of us are also very used to encountering challenges, barriers and exclusion in our day-to-day lives as we navigate the physical environment and services, systems and processes that are designed and delivered without any input from us.

Indeed, in 2016 the United Nations said the situation for disabled people in the UK was so bad that it amounted to 'grave and systemic' violations of three of our basic human rights – the right to independent living and being included in the community, the right to an adequate standard of living and social protection, and the right to employment (United Nations Committee on the Rights of Disabled People, 2016).

The Covid-19 crisis has served to highlight and aggravate these and other inequalities, and to put the human rights of disabled people at further risk.

# 2. What needs to change – a summary of the lessons to be learnt

The analysis of our survey responses offers key lessons for decisionmakers and service providers that need to be fully considered by government and other organisations in any measures or policies they adopt from here on, including preparing for future emergencies.

It tells us that the risk from Covid-19 is about more than simply risk to health. It tells us that the responses to this crisis pose just as much risk to disabled people and that many disabled people have experienced

violations of their human rights as a direct and indirect consequence of the crisis.

It demonstrates that disabled people's human rights can be at greater risk of being violated because of other factors including our gender, age, how much money we have, which Local Authority area we live in and if we live in an urban or rural area, for example.

There needs to be wide acknowledgement of the cumulative impact of interferences with human rights and the repercussions for various parts of our lives: without access to social care support we can't live independently, if we can't live independently we can find it difficult to work, and without work we have to rely on social security which impacts on our standard of living, without an adequate standard of living our mental and physical health is impacted, and so the cycle continues.

This report also shows that disabled people know best what the problems are and what is needed to resolve them. So, disabled people must be involved in determining, designing and delivering solutions. Excluding us from this denies us our right to have a say in the issues that affect us and risks creating more problems.

Ultimately, **Rights at Risk** tells us that disabled people must never again find ourselves so excluded and so poorly supported that we suffer the levels of despair highlighted in this report.

# 3. Disabled people's human rights and the risks posed by the Covid-19 crisis

All human rights belong to disabled people and we have our own Convention, ratified by the UK Government, which sets out how our human rights should be respected and protected – the United Nations

Convention on the Rights of Persons with Disabilities (CRPD). For more information about the CRPD see the UN website.

The following sections demonstrate how some of these rights have been diminished and put at risk during the Covid-19 pandemic, and what needs to change.

### 4.1 Risks to our right to live independently

Disabled people have the right to live independently, to be included in the community, to choose where and with whom to live and to have access to in-home, residential and community support services including the personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation.

#### Read the full text of Article 19 on the UN website.

What was the situation prior to the crisis? Many disabled people rely on social care support to enable them to live independently. But, in the face of Local Authority budget cuts, tighter eligibility criteria, and rising demand for social care that is fast outstripping investment, prior to the crisis many disabled people were only getting life and limb support and not the support they needed to meet their basic rights. In addition, most people in receipt of social care support must pay towards it, often from private income and benefits.

Even when the principles of dignity, respect and control are built into the fabric of national social care policies, as with Self Directed Support (SDS), we find that local authority budget constraints, inflexibility, lack of adequate infrastructures, and poor information and advice provision about options have frequently led to very poor experiences for disabled people, even though the policy has had 6 years to bed in.

There is still a large amount of unmet need for social care support, even for those who receive support, but this goes unrecorded.

What has happened since the start of the crisis? Our survey results show that this already precarious situation was made significantly worse by the onset of the pandemic.

Around 30% of respondents said that the social care support that they receive was either stopped completely or reduced, sometimes overnight and without warning. People were left in desperate situations as a result. Survey respondents told us they were forced to sleep in their wheelchair or left unable to get out of bed. Others told us they were unable to wash and dress themselves and keep up with basic household chores.

"I have gone from 20 hours of care (seven hours of which were personal care) to ZERO. I am now bedbound completely because of this."

People who care for and support disabled people, including disabled people who are themselves carers, told us that because of lost or reduced social care support they were forced to take over care and support responsibilities for family members. Around 40% of survey respondents told us that they have experienced changes or challenges with caring for children or other family members at home since the start of the pandemic.

Respondents told us about: the emotional impact of loss of independence and forced reliance on family and what this means for personal relationships; balancing new or increased caring responsibilities with work commitments; and managing conditions while also caring for others.

"My youngest child not being at school is proving difficult for my health as I'm now struggling to care for her 24 hours a day. I normally have 2 nights respite per week and one weekend daytime respite to rest in order to help me pace and cope. The stress and extra required activity is making my symptoms worse."

Many people across Scotland have not yet had their care packages reinstated. In some cases, they are still paying charges for care they no longer receive.

Whilst the Scottish Government announced an additional £100million for local authorities to be able to sustain social care support, it has been reported that this has not reached the people who need social care or third sector providers and there is no discernible evidence to show where this money has gone to and how it was used (Healthandcare.scot, 2020).

What could the long-term impact be? Some disabled people's lives changed dramatically and almost instantaneously when the country went into lockdown. People who have spent years organising and managing their own care and support (and often fighting for access to it) lost it overnight as authorities had little or no backup plans in place.

This has had a considerable emotional impact on people who felt abandoned by services at a time when they were most needed. It is likely that some disabled people will require more social care and other types of support as a consequence of their experiences throughout the crisis. This will consequently result in further increases in demand for services.

What needs to happen now? On 1st September 2020, the Scottish Government announced in its Programme for Government an independent review of adult social care, which will report by January 2021. This will include consideration of a National Care Service. As a starting point, any new system needs to enable those with social care support needs to access the resources and support they need, with genuine choice and control over who provides it and how they use it to live their lives, to achieve independent living, equal citizenship and fulfil their human rights.

It needs to be a system that is transparent and accountable to ensure that Scottish Government money designated for social care support is spent on social care support throughout Scotland and so that the system itself it resilient in times of national emergency, with no 'post-code' lottery for disabled people.

The pandemic brought into sharp focus that despite emergency funding from the Scottish Government to Local Authorities, provision for disabled Scots was reduced or removed. It is imperative that emergency funding for social care support finds its way to those it is supposed to benefit.

One way of ensuring this immediately would be for the Scottish Government to reopen the Independent Living Fund (ILF) to new applications and extend what funds can be used for. ILF funding enables individuals to pay for care so that they can be supported in their homes and within their local communities. However, it was closed to new applications in 2010. Reopening of ILF could be done immediately and would provide much needed support to people with high support needs.

## 3.2 Risks to the rights of disabled children

**CRPD Article 7 –** Disabled children have the same rights and freedoms as other children and must be able to enjoy these rights and freedoms on an equal basis with other children.

Read the full text of Article 7 on the UN website.

**CRPD Article 24** – disabled people have the right to education on an equal basis with others.

Read the full text of Article 24 on the UN website.

What was the situation prior to the crisis? Disabled children and young people have lower levels of educational attainment throughout their school life. Children with Additional Support Needs (ASN) are both less likely to achieve Curriculum for Excellence Levels (Scottish Government, 2019a) and less likely to leave school with qualifications than their peers without ASN (Scottish Government, 2020c). Children with ASN are also more likely to be excluded from school (Scottish Government, 2019c).

In addition, many disabled children and their parents rely on the vital support provided by schools, other services including respite services, and family members to survive on a day-to-day basis.

What has happened since the start of the crisis? Responses to our survey show that many families including disabled children lost some or all of the education and support for respite that they relied on and that people have had to step into caring roles or acquired increased caring responsibilities since the beginning of the Covid-19 crisis.

Parents of children with ASN told us that they felt 'abandoned' and noted the lack of support for disabled children who were not attending school.

Parents and carers were often dealing with the additional strain of having to educate children. This is more difficult for parents of children with additional support needs who felt that they do not have the skills or tools to teach or who could not find suitable resources online.

"We feel totally unsupported by the authorities, and as if disabled children and their families don't matter. Even our local Carers Association has no plans to stay in touch; the onus is on Carers to approach for help, and they're not offering any practical support anyway. We feel so alone in all this."

Numerous respondents reported that the children and young people they care for were experiencing increased anxiety which was sometimes resulted in violent behaviour or self-harm. Others told us that their children were exhibiting behaviours such as vocal tics, very low mood and other forms of challenging behaviour. Much of this was attributed to the removal of structure, daily activity, routine, face-to-face contact with friends, and access to the outdoors, and no help was provided to replicate these features at home.

"Son has ASD and self-harms/has suicidal thoughts. He is also really volatile and can hit out. He has no support at all now, as his main support was a school counsellor. I don't know how he will cope if this lasts much longer. I can't get out the house at all, as he won't come with me and can't be left alone."

This was causing parents and their children extreme stress and anxiety at a time when Child and Adolescent Mental Health Services (CAMHS) were least able to provide support. This was particularly extreme when service closure meant an adult or young person, who was previously in residential care or supported accommodation due in part to challenging behaviour, had to return to living full-time in the family home.

What could the long-term impact be? The loss of essential services and educational support has had a major impact on disabled children and their parents, especially the estimated 10,000 with 'complex additional support needs' (Scottish Government, 2020d). There will be many disabled children and young people left traumatised by their experiences during the pandemic and who will require mental health support to deal with this. The potential long-term impact on the educational attainment of disabled children is still to be seen but should be closely monitored.

It is also highly likely that young disabled people, particularly those leaving school, college and university over the coming years will be disproportionately affected by the recession and increasing unemployment. Labour Force statistics from the UK as a whole show that employment levels for those aged 16-24 and 65+ fell by 336,000 in May-July 2020, compared to the pre-pandemic quarter of January (House of Commons Library, 2020). It is also known that those sectors of the economy most badly affected by lockdown have a disproportionate number of young, low paid workers employed in them.

What needs to happen now? As we progress through the phases of moving out of lockdown, action is needed to support disabled children and young people and their families, both practical and emotional, to recover from the impact of the initial lockdown phase, reported above.

Local authorities must ensure that they are actively identifying and providing additional support to children with "complex additional support needs" who lost out on support to meet their needs because of school closures.

The Getting It Right For Every Child' (GIFREC) policies and guidance should be future-proofed to ensure that they support any further sudden changes to circumstances resulting in loss of support, such as we saw with the onset of the pandemic.

Schools need to recognise that many families of disabled children are digitally excluded and should ensure that they 'access proof' their alternative ways of working for use during any future lockdown situation. This should include taking steps to provide support for online education, so that it is accessible and inclusive, as well as alternatives to it. For example, online videos should be checked to ensure that they are accessible for Deaf or deafened children and young people.

It should also be acknowledged that home computers and broadband can be beyond the means of many families that include disabled people, who are more likely to be living in poverty and living in socially rented housing. The Scottish Household Survey 2019 showed that 22% of low income households did not have home internet access; 79% of those in social rented housing had internet access compared with 91% of households who owned their home. In addition, 71% of adults who have some form of limiting long-term physical or mental health condition or illness reported using the internet compared to 94% of those who do not (Scottish Government, 2020e). Alternatives to online resources should be provided for those who live in homes without digital access.

The Scottish Parliament should deliberate and pass the United Nations Convention on the Rights of the Child (Incorporation) (Scotland) Bill.

## 3.3 Risks to our right to an adequate standard of living and social protection

**CRPD Article 28 –** Disabled people have the right to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions.

#### Read the full text of Article 28 on the UN website.

What was the situation prior to the crisis? We know that households with at least one disabled adult are more likely to live in relative poverty and experience material deprivation, and that households containing a disabled person have higher levels of child material deprivation (Scottish Government, 2019b). Over the last ten years, disabled people have been greatly impacted by UK Government cuts to benefits labelled 'welfare reforms' and over half of all the cuts made have fallen on disabled people and their families. There is ample evidence to show that disabled people have suffered catastrophic consequences as a result of the UK Government's 'welfare reform' agenda.

In 2016, the UN Committee on the Rights of Disabled People inquiry found the UK to be in breach of Article 28. It said that:

"The cumulative impact in the reduction of welfare benefits had led persons with disabilities to struggle to maintain a minimum level of income, driving many into increased dependency on relatives and increased levels of indebtedness, resulting in an inability to manage the bare essentials and having to have recourse to food banks."

An already dire situation for some disabled people was therefore the backdrop of the Covid-19 crisis.

What has happened since the start of the crisis? The Covid-19 crisis upended many of the systems and networks disabled people relied on to meet their most basic needs — including getting access to basic items like food and medicine. Loss of social care support and shielding or self-isolating meant that some disabled people were not able to go to the shops and had to find alternative arrangements or put themselves at risk by leaving their homes.

Our survey showed that over half (53%) of respondents experienced difficulties accessing food for themselves or those that they care for. Over a quarter of respondents reported having difficulty in obtaining the medicines needed to maintain their health. 1 in 8 people at high risk from Covid-19 reported not being able to effectively shield or isolate themselves because they did not have other support to access food and/or medication.

"I have had to break my [shielding] to buy food, putting myself at risk. Medicine pre-ordered online now needs 7 days' notice to allow GP surgeries/chemists to cope with demand. Also, I usually collect my medicines from local chemist, it's proving difficult to change this to have it

delivered during Covid-19 pandemic. Again, I've had to break [shielding] to queue and collect my meds."

Responses to our survey and press coverage of these issues show that many of the difficulties disabled people experienced were because of inaccessible systems and processes that were put in place without consulting disabled people. Initiatives like "vulnerable" shopper lists created anxiety for many disabled people who were unable to get themselves added to the list so that they could secure delivery slots.

Our survey also found that physical distancing rules within shops were impacting people who require assistance to do their shopping, and people with mobility issues reported difficulties queueing up to get into shops.

Other respondents raised concerns about increased costs at this time as a result of: having to take more expensive options; lack of reduced bargains; limited choice of where they could shop meaning they could not shop around; and increased heating and electricity costs due to staying at home more.

For respondents living in rural areas the problems they experienced in accessing food and medicines were compounded by their distance from services and the withdrawal of bus services.

"The buses aren't running to my area anymore. We only have a corner shop in walking distance and they don't have essential items like toilet roll. We usually do our shopping online but there are no delivery slots."

The Covid-19 crisis has also affected access to social security benefits for some people. One in ten (10%) respondents to our survey said they have experienced a negative impact on their access to benefits because of the Covid-19 emergency. A further one in six (17%) expected to face problems in the future. Respondents told us there was confusion and delays when interacting with the social security system, and some people were unable to get the support they needed to make a claim.

What could the long-term impact be? The incoming recession, leading to rising prices and increasing unemployment, makes it is almost certain that more and more disabled people will have to rely on social security for their income. In turn, we will most probably see more disabled people pushed into poverty, debt and homelessness.

Disabled people are rightly worried about the economic downturn, how it is going to affect the welfare state and the level of benefits for disabled people in the future. The last financial crisis and resulting austerity measures had a catastrophic impact on disabled people. Governments must learn from this and avoid repeating the disastrous failures of the not so distant past.

What needs to happen now? If, as is predicted, increasing numbers of disabled people become unemployed, it is vital that the social security system provides a realistic safety net which prevents more disabled people from falling into poverty. We believe that there are a number of measures that the UK and Scottish governments can take to ensure that this happens.

The UK Government should increase the level of legacy benefits by £20 a week to reflect the temporary increase in Universal Credit standard allowance, announced by the chancellor in March in response to the

crisis, in order to prevent the development of a two-tier system of support that would disadvantage those people (including significant numbers of disabled people and people living with long term conditions) on legacy benefits.

Covid-19 has increased daily costs for disabled people already struggling to make ends meet. Since the lockdown began on 26 March, many have had to change care arrangements, switch to online deliveries for essentials, start to pay for Personal Protective Equipment and supply cleaning products to protect their carers. Of 224 disabled people surveyed for a week in mid-April, the Disability Benefits Consortium reported that 95% saw costs rise for food, utilities and managing their health. All extra costs resulted directly from the Covid-19 emergency (House of Commons, 2020).

In this context it is vital to ensure that claims for Personal Independence Payment (PIP) are dealt with quickly. Indications suggest that people are struggling to make claims for disability entitlements and are facing significant delays in getting their claims processed (Disability Rights UK, 2020).

The Scottish Government has had to delay the introduction of the new disability assistance benefits it assumed responsibility for in April due to the pandemic. The Scottish Government must set out its revised timescales for launching all the new benefits as soon as possible. In addition, the Scottish Government needs to start a fundamental review of disability assistance to ensure adequacy and support for independent living, as set out in a recent report from the Scottish Campaign on Rights to Social Security (SCoRSS, 2020).

Local authorities should also take steps to urgently identify and offer support to disabled people who continue to shield (especially since most formal shielding support has currently stopped). We know some disabled people, including those who were never on the official 'shielding list' continue to shield because of their understanding of their own health or long-term condition. In addition, disabled people who are required to self-isolate if they have symptoms, are awaiting a test or have tested positive must also be provided with support to get access to the things they need during this period, including essential items like food and medicine.

Finally, the pandemic has highlighted that disabled Scots have struggled to access food. Any future Scottish Bill on the Right to Food should address the issues that hinder disabled people's access to and enjoyment of this human right.

## 3.4 Risks to our right to employment

**CRPD Article 27 –** Disabled people have the right to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive, and accessible to disabled people.

Read the full text of Article 27 on the UN website.

What was the situation prior to the crisis? Disabled people in Scotland are more likely to be unemployed than non-disabled people (Scottish Government, 2020a). The barriers disabled people face in getting ready for, getting into, staying in and getting on in work are many, varied and complicated. They include stigma, poor attitudes, inaccessible application processes and discriminatory practices including less opportunities for promotion and development and

obstructive retention and sick-leave policies. Inaccessible transport and workplaces and a lack of accessible housing can also play a part in preventing disabled people from finding or progressing at work. The fact that many disabled people have fewer educational qualifications because of exclusion and discrimination within education also contributes to pushing us further away from accessing working life.

What has happened since the start of the crisis? Employment inequalities are well entrenched, but the pandemic has supercharged these and already we can see the impact on disabled people's employment prospects.

A greater proportion of disabled people are employed in public administration, education and health, as well as the distribution, accommodation and catering sectors, compared with the non-disabled population (Scottish Government, 2020a). These sectors have been hit hard by the Covid-19 crisis and could see many jobs lost, with a disproportionate impact on disabled people.

In addition, these are industries where workers are likely to meet other people. Around one fifth (22%) of respondents to our survey (disabled people and people supporting/caring for disabled people) told us that either they, or family members worked in a job that puts them at risk of coming into contact with the virus. Many told us that they or family members were key workers. Disabled people may therefore be at greater risk than non-disabled people of coming into contact with the virus in the workplace.

Some of the disabled people who responded to our survey said they were worried about being exposed to Covid-19 in the workplace. Other respondents who were shielding told us of their worries about shielding

while living with key workers. Many stressed that at the time they responded the key worker they lived with had no access to Personal Protective Equipment (PPE) at work or at home and that they were concerned about the transmission of the virus at home.

"There are 4 four people living in this house. Two of us are trying to shield, 2 are key workers. No PPE for anybody. You can imagine the stress."

Although some respondents told us they were able to work from home, others said they had worries about losing their job. Some were worried about declining health (because of lockdown and missed medical appointments) and the long-term impact this will have on their ability to work.

"If I do lose my job, it will be indirectly because of Covid-19. All my support and treatment got stopped because of Covid-19, my health significantly worsened as a result to the point where I was hospitalised and my manager has informed me my job is now at risk due to the length of my sickness absence."

Others told us they were worried because they were not on the official shielding list but nevertheless had conditions which put them at risk if they contracted Covid-19. These people reported concerns that they will have to make the decision to put themselves at risk and go back to work or lose their job.

In terms of more positive evidence emerging from the lockdown, many respondents to our survey reported that their employers had been

supportive and had moved to alternative working arrangements with relative ease. A few respondents commented on how adjustments to ways of working that were normally not available have suddenly been made with little fuss or difficulty. Disabled people have been asking for adjustments to ways of working for decades and for some there is an uncomfortable irony at the speed adjustments long considered impossible to make by employers were put in place during lockdown.

"Suddenly, mysteriously, all the simple adjustments to enable distance working that I've previously been assured were impossible have started to be made. I hope that they remain available from now on."

What could the long-term impact be? To date, the pandemic has had more of an impact on the labour market status of particular age groups. Employment levels for those aged 16-24 and 65+ fell by 336,000 in May-July 2020, compared to the pre-pandemic quarter of January-March 2020. In comparison, employment levels for those aged 25-64 have increased by 171,000. Some workers are disproportionally economically impacted. Workers who are from a BAME (Black, Asian, Minority Ethnic) background, women, young workers, low paid workers and disabled workers, have been most negatively economically affected by the Covid-19 outbreak. 15% of workers in shut down sectors are disabled (House of Commons Library, 2020). Overall, official statistics continue to show increases in unemployment (Scottish Government, 2020b) which are likely to continue for some time, particularly when the furlough scheme ends in October 2020.

The fears about employment of those disabled people who responded to our survey are far from groundless. During the 2008 financial crisis and the recession which followed it disabled people in Scotland were more likely to lose work than their non-disabled peers.

This suggests that any negative impact on the overall employment rate arising from the Covid-19 emergency is likely to be disproportionately felt by disabled people and to be of a more prolonged nature.

Some disabled people who were shielding said that they had additional worries about having to go back to work as lockdown is lifted. Without a vaccine it is difficult for some people to feel confident about returning to their workplaces and interacting with others.

What needs to happen now? If, as we expect, disabled people are disproportionately affected by job losses, the Scottish Government's target to half the current employment gap of 36% between disabled people and non-disabled people by 2038 will not be met. Specific labour market measures must therefore be taken now, and the Fairer Scotland for Disabled People Action Plan urgently overhauled both to protect the jobs of disabled people still in work and to increase the skills and employment opportunities of those who become unemployed.

Effective and accessible employability support must be made available to disabled people. If the Scottish Government's current employability service, Fair Start Scotland, is to improve on its current poor success rate with disabled job-seekers, both the leaders of the programme and the individual providers need to work in partnership with DPOs who could provide insights into their experience and practice in supporting successful work experience placements. Such partnership work needs to be properly resourced and funded. As the scheme has recently been

extended for a further 2 years it is vital that realistic targets are set for providers for supporting disabled people in chosen and sustained employment, with full transparency and accountability for achieving those targets.

The Scottish Government Programme for Government also announced £100 million of additional funding for employability work to support people to move into work or to retrain. The package of support will see at least £50m of that funding set aside to help young people get into work. It is essential that young disabled people are treated as a priority group for access to the Jobs Guarantee Scheme and other employability support or they could suffer life-long consequences. It is also important that a proportion of the budget is set aside to support full accessibility. DPOs should be involved in ensuring that this happens and be funded to contribute to this.

The Covid-19 crisis has shown just how easy it is for employers to make adjustments to ways of working. This must continue as the country moves out of lockdown. The Scottish Government should work with employers to ensure flexibility in working hours and arrangements is guaranteed for employees through the adoption or updating of flexible and accessible working policies. Employers should also learn from the experiences of their disabled employees and use this experience to inform their policies. It should be acknowledged that not all new ways of working are accessible and that there must be flexibility which takes account of people's individual needs.

Changes made to the Access to Work programme by the Department of Work and Pensions (DWP), although welcome, were inadequately communicated to disabled people. The DWP, and the Scottish

Government as part of their Fairer Scotland for Disabled People Employment Action Plan, must make sure that they are communicating with disabled people and employers accessibly and effectively.

The DWP should retain the changes they have made to the system but also bring in further changes to ensure that the programme is fit for purpose. These include: allowing people to use their equipment at home and at work; accepting the need to provide duplicate equipment if people are working in different locations; allowing complete electronic submission of claims, with e-signatures by all parties and e-submission of evidence; increasing capacity and efficiency of the processing so that applications are responded to and dealt with faster.

## 3.5 Risks to our rights to physical and mental health and risks to our right to life

**CRPD Article 25 –** disabled people have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.

Read the full text of Article 25 on the UN website.

**CRPD Article 10** – Everyone has the right to life, including disabled people and disabled people must be able to enjoy their right to life on an equal basis with other people.

Read the full text of Article 10 on the UN website.

What was the situation prior to the crisis? Disabled people are less likely to report good or very good health and more likely to report poor mental wellbeing than non-disabled people. We are also less likely to meet physical activity recommendations and more likely to engage in

health risk behaviours such as smoking or harmful drinking than nondisabled people (Scottish Government, 2019b).

Many disabled people rely on regular appointments with a wide variety of health professionals to receive medication and treatments. Others rely on exercise, such as swimming, or peer support networks through weekly clubs or classes, to look after and maintain their physical and mental health.

What happened since the start of the crisis? Disabled people told us that they have lost access to health services and support for both physical and mental health. 7% of people responding to our survey said that their medical appointments and/or routine health services were cancelled or reduced since the start of the crisis.

"Physio services are suspended. Wound dressings supplied to apply personally (no medical assessment). Follow up X-ray/dietician delayed."

People spoke about their worries in relation to not being able to get medical appointments or routine health services and reported missing out on physiotherapy, pain clinics, injections, neurology appointments and other vital services.

Though we did not ask a specific question about 'do not attempt resuscitation' (DNAR) notices, 4 respondents told us that they or someone they know had been asked to sign a DNAR notice or informed that they would not be ventilated should they contract Covid-19. Numerous others reported that their mental health has been impacted by the worry that they might be denied treatment because of their impairment(s).

"I am extremely anxious about the impact of Covid19 and my greatest fear is that, if I were to
experience complications from the virus and
require admission to hospital, as a disabled person
I would not receive the same care that I would as an
able-bodied person. I am worried that my life is
viewed as less valuable because I'm a wheelchair
user..."

One of the starkest findings from our survey is the impact that the pandemic has had on the mental health of disabled people. Disabled people with and without pre-existing mental health conditions found everyday life under lockdown extremely stressful.

15 disabled people with existing mental health problems reported to us that they were feeling suicidal at the time they responded.

## "I am so lonely and feel so depressed. I feel suicidal."

Many hundreds of others told us about the stress and anxiety that they have experienced due to a number of issues. People told us they were anxious about their own health, the health of those they care about and many were very fearful for the future.

What could the long-term impact be? The cumulative impact of many of the other issues we have discussed elsewhere in this report have understandably caused a significant amount of stress and uncertainty which has resulted in serious detrimental impacts on mental health.

Furthermore, the long-term impact of cancelled medical appointments, as well as the impact of shielding with little or no physical exercise, remains to be seen. Disabled people are worried that these factors will result in declining physical and mental health, some of which people are already experiencing.

What needs to happen now? NHS Scotland must inform people about the reopening of health care and treatment and what they need to do to reschedule appointments including remote appointments. These need to be accessible and inclusive of disabled people such as those with communication needs. Guidance should be issued to clinicians about prioritising appointments and making reasonable adjustments for those who continue to perceive themselves to be at high risk from the virus. In addition, the Scottish Government must respond to evidence from disabled people managing chronic pain conditions during the crisis and ensure that disabled people can safely access leisure and exercise facilities to help them to manage their condition.

It must also be acknowledged that if people have experienced deteriorating health since the start of the pandemic they may require changes to their health care and treatment and their social care support. There must be adequate resources in place to ensure people get access to the care and support they need.

The Scottish Government must monitor the health outcomes of disabled people to understand the long-term impacts of the pandemic, particularly on those who have been shielding and those whose social care support packages were cut.

If there is a second wave of the virus the Scottish Government needs to expand shielding policies and support. This support cannot simply apply to those disabled people with a limited number of medical conditions who previously received an official shielding letter. The Scottish Government should work with disabled people to fully review the criterion and the limitations of its shielding policies and processes so that those who need to shield again can access the guidance and support to enable them to do so safely.

Finally, we know that in England and Wales three-fifths of people who have died from Covid-19 were disabled people (Office for National Statistics, 2020). No equivalent figures have been published in Scotland. Although Public Health Scotland are producing breakdowns by gender, age and deprivation quintile, there is no data on the numbers of disabled people dying with Covid-19. The Scottish Government should ensure these statistics are published urgently. Such data is essential to inform decisions on future prevention and planning and to ensure the needs of disabled people are fully taken into consideration.

## 4. Conclusion

Our survey results show that the risks posed by the Covid-19 crisis go much further than simply a risk to health for disabled people who contract the virus. The risks posed by the crisis and the responses to it are risks to disabled people's human rights. Although exclusion, discrimination and interferences with our human rights have long been everyday occurrences for many disabled people, the Covid-19 crisis has aggravated these in ways which will have consequences far into the future.

What we saw from our survey results is backed up by international research looking at the impact of different kinds of emergencies on disabled people and our rights. In line with our findings, this body of

evidence tells us that disabled people have fewer resources to support themselves through an emergency and are disproportionately affected, under-considered, and under-served by official responses in times of emergency. It is therefore no coincidence that disabled people, who have been persistently marginalised by society, are experiencing the worst effects of the Covid-19 crisis.

Inclusion Scotland has identified key actions that need to be taken by Scotland's policy and decision-makers, service providers, employers, retailers, academics, funders, broadcasters, and wider society to address the concerns raised in this report. They apply not just to those policies or services specifically about disabled people, but across all the policy areas that affect us. Our key messages to decision makers are as follows:

- 1. Stop stigmatising disabled people as vulnerable and problematic
- 2. Promote, don't diminish, our human rights as disabled people by ensuring human rights-based approaches to policies and practices are the standard including by taking action to incorporate the United Nations Convention on the Rights of Disabled People (CRPD) into Scots law
- 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

By taking these actions we believe that the risks posed to disabled people's human rights by the Covid-19 crisis can be minimised and mitigated. We also believe that these actions are key to shaping what happens next and to ensuring we do not return to the pre-Covid-19

situation which did not work for disabled people and which ultimately left us exposed at a time when we most needed our human rights to be protected.

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