The impact of COVID-19 on disabled people in Northern Ireland

Executive Summary



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New Decade New Approach Nothing About Us Without Us





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'States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, 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.'

(Article 11, United Nations Convention of the Rights of Persons with a Disability)



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The pace at which the global pandemic took hold was truly unprecedented; in a number of weeks, everything we all knew to be 'normal' changed utterly. What became very clear, was the feeling of many disabled people that their voices were being lost in the noise or worse simply ignored in the confusion and panic that was unfolding. Many people were frightened about the future.

Like so many others, we worked at pace, adapting every single service and resource we had to meet the demands for support from our community. During this time, we fielded innumerable calls, emails and held video meetings with individuals, families, organisations and government.

We wanted to do our best to get a clear picture in time of the reality for disabled people on the ground and provide a forum for people to share their lived experiences of the pandemic. We will share this information with policy and decision makers to ensure that disabled people's voices are listened to, and their rights are respected.

We published an online survey to gather the experiences of disabled people, their families and carers and received 404 completed surveys, including over 1300 written statements. Their responses were gathered from 1 – 30 April 2020, which was two days after lockdown and shielding measures came into effect on 28 March 2020.

While the survey captured respondents' experiences within key categories, it quickly became evident that many were experiencing multiple challenges at the same time. Within their responses, challenging circumstances emerge that highlight the sudden and substantial impact COVID-19 has had on their lives.



Key Findings



Social Care

35% (140) of respondents indicated COVID-19 had impacted the social care support they normally accessed; 11% (45) indicated their social care had not been affected but they were concerned about the future. For those who

had been impacted there was no difference identified between urban and rural areas. Of the people who provided comments, 39 described complete cessation of support they normally accessed. Eleven of these respondents had reduced or cancelled their social care to protect themselves or loved ones in response to their concerns about hygiene, lack of Personal Protective Equipment (PPE) and contracting COVID-19.



Physical Health

56 respondents described a decline in their physical health relating to limited exercise / getting outdoors, difficulties accessing medications and cancellation of routine medical treatment. 240 (59%) of respondents

indicated they had a condition that placed them at high risk of contracting the virus, but only 96 (24%) had received a shielding letter. 96% (390) had not discussed or received correspondence relating to 'do not resuscitate' or end of life decisions; however comments indicated a high level of worry and anxiety that they, or someone they care for would not be able to access treatment for existing medical needs, and / or would be denied medical intervention if they contract COVID-19.





Mental Health and Emotional Wellbeing

72% (294) of respondents indicated the impact of socially isolating was affecting their mental health and emotional wellbeing. Comments describe worsening of pre-existing mental health conditions and the development of new

symptoms; many described feeling anxious about contracting COVID-19, being isolated from family and friends, and not being able to access existing support from their General Practitioner or Mental Health Team.



Carers

38% (156) of respondents reported changes or challenges with caring for children or other family members at home relating to disability. Comments provided indicated this was negatively impacting mental

health and emotional wellbeing. Respondents related this to limited or ceased social care support, closure of schools, day centres or other activity centres, and working from home.



Accessing Food and Medicine

Over half of respondents (57%) had experienced disruption accessing food or medicine, with an additional 46 people who were managing at present but had concerns about future access. Difficulties accessing

home deliveries and priority lists with major supermarkets, additional costs and increased reliance on others had led to a loss of privacy and independence.



Accessing Information

Almost three quarters of survey respondents (68%) indicated they were able to access health and public information about COVID-19, with an additional 59%



(190) having access to information specific to their health needs in relation to the pandemic.



Employment and Training

4% (15) respondents indicated they had lost their job as a result of the pandemic, with 28 raising concerns about the future stability of their employment. 14% of respondents said their training or further education had

been disrupted. Of those who provided comments, four had been furloughed and two described how increases in their role as a carer meant they had to leave their job to provide full time care. For some, the pandemic has facilitated the opportunity to work from home, an option previously deemed unsuitable by their employer.



Social Security Benefits

68% of respondents reported that they have not experienced problems accessing social security benefits. However, 22% say they have had problems accessing benefits or anticipate they will have problems in the future. Nine people specify being in the process of applying for

benefits or appealing a decision and having that process delayed by the pandemic.



Community Support

Less than half of those who completed the survey (35%) were or had received support from volunteers in their community. 63% of disabled people and people with long-

term health conditions who responded said they were providing support to others in the community who had been impacted by COVID-19. Comments provided related to making PPE, donations and contacting others to offer assistance / emotional support.



Our Recommendations

While the progression of the pandemic and its subsequent impact has evolved since our survey was carried out, the experiences outlined broadly reveal the fragility of independence for disabled people and raise questions about the strength of disability rights in the face of such a crisis. As a result, we respectfully call on the Northern Ireland (NI) Executive Government to consider our following recommendations.

Disability Strategy: Prioritise the timetabling, development and resourcing of a new world leading disability strategy

The visibility and meaningful involvement of disabled people in this work is critical. Previous strategies have failed for a variety of reasons, many in the disabled community feel these failures of the past rest on a missed opportunity to meaningfully involve them or prioritise their rights. We now have an opportunity for change.

Mental Health: Prioritisation of the mental health needs of the NI population, with emphasis placed on those already identified at highest risk

The pre-pandemic challenges regarding the mental health and wellbeing of the local population are well documented, including the impact of living in a post conflict society. We have the highest rates of mental health difficulties within the United Kingdom (UK). Our findings amongst many other similar reports, demonstrate the pandemic has further compounded the mental health of disabled people and their carers.

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Data Collection and Sharing: Ringfence appropriate resources to enable better availability of historic and future disaggregated data in relation to disability in NI

A major challenge facing disabled people, the third sector and Government is the limited, and often disparate data held in respect of disability specific to NI. Given the total population size of NI, we can and should have a better understanding of those with a disability who make up 1 in 5 of the entire population.

Reforming Social Care: Produce as a matter of urgency a timetable for moving reform of adult social care forward in NI

The evidence emerging throughout the COVID-19 Pandemic has been a further universal recognition, building on considerable work to date that social care in NI is at breaking point. Disabled people are fearful of regression of their right to live independently and of the ongoing framing of social care as something linked to older people. Carers feel hidden, undervalued and forgotten about.

Right to Medical Treatment: Publish without delay the Department of Health 'COVID 19: Ethical Advice and Support Framework' and to commit to ensuring this is cascaded to all healthcare professionals

Failure to be treated equally in respect of COVID-19 was and continues to be a significant source of worry for disabled people and their families. The Minister's public commitment to NHS Principles of treatment was critically important. Issuing an ethical treatment framework grounded in a rights-based approach is an important next step.

Role of Carers: Take immediate steps to acknowledge and recognise the often silent, unseen but vital role of carers, not only in supporting some in the disabled community but right across our society

COVID-19 has highlighted once again the essential role that carers play. Effectively a hidden pillar in our health and social care system. We are

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calling for more support for carers, with an immediate rise in Carers Allowance and access to other services to better support their physical and mental health.

Accessing Food and Medicine: Review the issue of prioritisation of food and medicine delivery for disabled customers during COVID-19

We believe there is considerable learning possible in how this matter was approached by some supermarkets. It was notable during the pandemic that small stores were quicker and more willing to adapt to a prioritised home delivery system without need for "proof". We believe that working together, using principles of co-design the system can be significantly improved for all going forward.

Employment and Training: We are respectfully calling on the Ministers for Communities and Economy to ensure that emergency/forward planning in respect of Employment and Training supports during and post COVID are done in partnership with disabled people and their organisations

Ensuring job opportunities, job retention and job progression in the new COVID landscape will require highly specialised solutions that reflect the unique challenges disabled people are facing.

We believe that this period calls for further innovative piloting and solutions that can ensure that disabled people are not hit the hardest in recession.

Volunteering: Recognise the importance of disabled people as not only passive recipients of volunteer support but also active participants in volunteering during the COVID-19 Crisis

We are calling for a commitment to working with disabled people and the sector in advancing the numbers of disabled people who volunteer. Disabled people face additional barriers to exploring and participating in

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volunteering opportunities in NI. In the decade ahead, it is now more critical than ever that these barriers are removed.

Support for DPOs and the wider sector: Identify the long-term support needs for disabled people and their organisations.

It is critical the mechanisms to have our collective voices heard are resourced and supported to not only survive, but thrive. The importance of having representative organisations cannot be overstated. The work undertaken by so many during the COVID-19 pandemic was done against a backdrop of a decade of austerity. It is critical opportunities are created to allow organisations to remain open, rebuild and contribute to 'building back better'.

Co-production: Prioritise a co-production framework to underpin our journey towards recovery and resilience.

Since the onset of the pandemic, co-production of recovery plans has been problematic due to the necessary speed needed for management and planning processes. However disabled people have felt their voices are being lost or ignored. In response to the impact of the pandemic, a co-production framework that fully engages with the expertise of disabled people and their carers is essential.



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