

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



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**New Decade New Approach
Nothing About Us Without Us**



Authors:

Sean Fitzsimons

Dr Emma O'Neill

Dr Alison Crawford

Published by Disability Action Northern Ireland (NI)

Telephone: 028 9029 7880

Textphone: 028 9029 7882

Website: www.disabilityaction.org

An Easy Read version of the Executive Summary of this report is available



‘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)



Executive Summary

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.



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



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-19 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



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

Support for Disabled Peoples Organisations (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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1.0 Introduction

Disability Action is a pioneering disability rights organisation, comprised of dedicated individuals who work to promote, protect and uphold the rights of disabled people here in Northern Ireland and around the globe.

For over 30 years we have worked with our community, members and Government to educate, inform and advance the disability equality and rights agenda.

21% of adults and 6% of children living in private households in NI have a disability and the incidence is one of the highest in the UK.

As a campaigning body, we work to bring about positive change to the social, economic and cultural life of disabled people and consequently our entire community. In pursuit of our aims we serve 45,000 people each year.

1.1 Background

It is critically important to look at what follows in this report in recent historical context. The decade beginning 2010 to 2020 saw disabled people in Northern Ireland and across the UK being subjected to deeply regressive policy and political decision making on an unprecedented scale.

It would be impossible to summarise the depth, complexity and impact of these decisions here in this report, but there are many notable examples of wider reading [\(1\)](#).

As an organisation we worked in partnership with others across the UK to monitor the UK State's implementation of the United Nations Convention



of the Rights of Persons with a Disability (UNCRPD) during this time [\(2\)](#). We shared our findings directly with the United Nations in the form of the collective Shadow report [\(3\)](#).

Chair of the CRPD Committee Theresia Degener's comments to the UK state during its examination in 2017, while shocking to some, came as no surprise to disabled people. They speak to a decade of devastation:

“Evidence before us now and in our inquiry procedure as published in our 2016 report reveals that social cut policies have led to a human catastrophe in your country, totally neglecting the vulnerable situation people with disabilities find themselves in.” [\(4\)](#)

It is important to remember that from January 2017 – January 2020 Northern Ireland did not have a Government. Policy decisions relating to disabled people's lives in NI were therefore left in the hands of local civil servants (who, in the absence of Ministerial authorisation, often felt powerless to act). Meanwhile, politicians in Westminster grappling with Brexit and a myriad of other 'bigger' issues, seemed entirely removed from addressing the challenges disabled people and their families in NI were facing.

A Glimmer of Hope - A New Decade and a New Approach?

The Political agreement 'New Decade, New Approach' was reached on 9th January 2020. It sent out a positive signal, with commitment given to setting out a timetable for a new disability strategy, advancing the sign language Bill and abiding by principles of co-design and co-production [\(5\)](#).

COVID-19

The pace at which the global pandemic took hold was truly unprecedented; in a number of weeks, everything we knew to be 'normal' changed utterly. Many people were frightened about the future.



Disability Action's Response

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.

Our work during this time has been a mixture of both highly visible and discrete.



Some examples include: the repurposing of all transport vehicles to deliver food and medicine across NI, supporting vital disabled front-line workers to stay in work and equally those unable to.

What became very clear, was the feeling of many disabled people that their voices were once again being lost in the noise or worse, simply ignored in the confusion and panic that was unfolding.

Survey

We published an online survey in April 2020 to gather the experiences of disabled people, their families and carers during COVID-19 in NI. We wanted to do our best to get a clear picture in time of the reality for disabled people on the ground.

The survey went live on April 1st and closed on April 30th. We received over 400 survey responses, which included over 1300 written statements.

What follows are our key findings and recommendations.

We intend to share this information with policy and decision makers to ensure that disabled people's voices are listened to and their rights are respected. Furthermore, we must ensure their much-



needed expertise is brought to all tables as we plan collectively for recovery and resilience.

We want to thank everyone who contributed to this survey. Many disabled people and their organisations have worked tirelessly alongside us to protect the rights of disabled people now and moving forward through this period.

The response from our community during this crisis has demonstrated once more our unmatched skills in resilience, adaptability and lateral thinking.



400 survey responses, which included over
1300 written statements



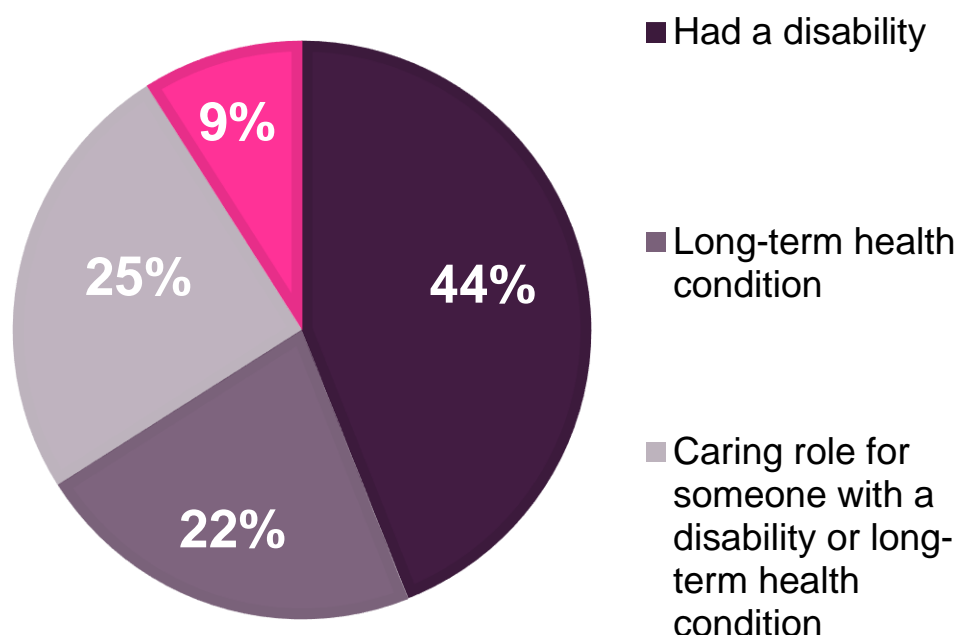
2.0 Methodology

2.1 Design

A survey was designed to capture a 360-degree perspective of how COVID-19 was impacting disabled people in NI (Appendix 1). The survey was advertised via Disability Action NI social media and open to respondents from 1st April 2020 – 30th April 2020.

2.2 Sample

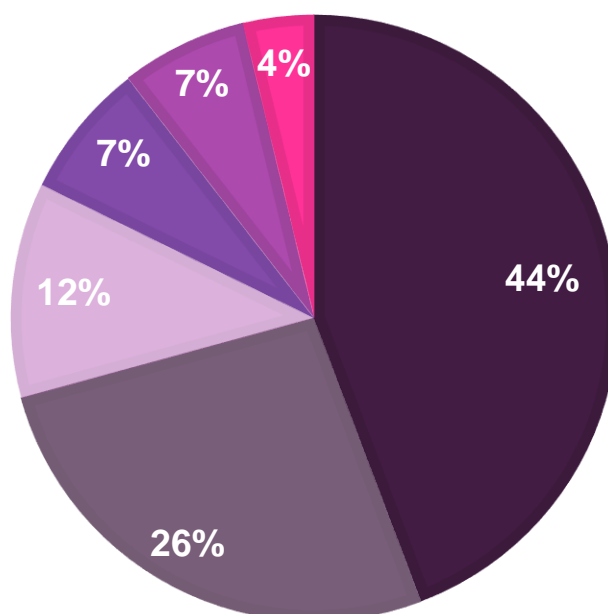
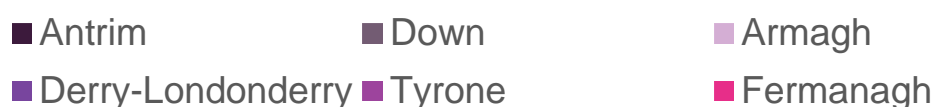
In total 404 people completed the survey; 44% indicated they had a disability, 22% a long-term health condition, 25% had a caring role for someone with a disability or long-term health condition (within this figure 10% also indicated they had a disability or long-term health condition) and 9% indicated they were a non-disabled person.





Most respondents lived in County Antrim (177) and County Down (106), followed by Armagh (46), Derry / Londonderry (29), Tyrone (27) and Fermanagh (15). Additionally, respondents mainly lived in cities (120) and towns (125) with the remainder living in rural areas (156).

LOCATION OF RESPONDENTS BY COUNTIES IN N.IRELAND



2.3 Analysis

Data was cleaned to eliminate incomplete and missing responses. Qualitative data was then analysed using Thematic Content Analysis (TCA) and Grounded Theory to develop themes and sub-themes from the data [\(6, 7\)](#).



3.0 Findings

Analysis of the survey data produced nine overarching themes, underpinned by 38 sub-themes, as shown in Table 1. Each are detailed individually however they do overlap, connect, and resonate with each other.

Table 1: Themes and sub-themes

Theme	Sub-theme
3.1 Social Care	Reduction Cessation PPE and risk Communication Alternatives
3.2 Physical Health	Risk and shielding 'Do Not Resuscitate' Symptoms Medication Treatment Exercise
3.3 Mental Health and Emotional Wellbeing	Social isolation Pre-existing conditions Fear of COVID-19
3.4 Carers	Family support Reliance on others Increased role Mental health



3.5	Accessing Food and Medicine	Delays Priority status Costs Loss of independence Privacy
3.6	Accessing Information	Accessible Delays Confusion
3.7	Employment and Training	Furlough Caring role Support from employers Risk Working from home
3.8	Social Security Benefits	No changes Assessments Delays
3.9	Community Support	Help from volunteers Helping others Eligibility

3.1 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 respondents described complete cessation of support they normally accessed.

“Day centre closed, domiciliary carers cancelled, respite cancelled until further notice...”

Twelve respondents described a reduction in the amount of assistance they normally received.

“Care agency has cut shower from 2 a week to 1 a week...”

“I used to get 4 carer calls a day which has been cut down to just a morning call...”

Eleven respondents commented that in response to concerns about contracting COVID-19, hygiene and no PPE, they had reduced or cancelled their social care to protect themselves or loved ones.

“I cancelled my trust morning care call as the carers wore no PPE and failed ever to wash their hands coming into my home and I am immunosuppressed...”

“I had to reduce the amount of Domiciliary calls as I was worried about some carer’s lack of hygiene and they were dismissive of the dangers of COVID-19”

Two people described how this placed them at significant risk of harm.

“Have no help on ventilator and legally need 3 people to hoist safely...”

“Having to help disabled person shower who takes seizures and he is normally assist x 2 and I’m doing it on my own”

Despite changes to their social care support, of those who provided comments, respondents experienced difficulties communicating with their social worker.



“My social worker stopped contact...”

“Social worker hasn’t been in touch to see how he is...”

Of those who did describe contact with their social worker, they explained there were no alternatives support options available to them.

“Respite care for the disabled person I care for has been taken away, no additional support...”

“Can’t go to day care. Personal assistant not able to carry out usual tasks. No alternative day activity/social support offered...”

One person explained that, while they were offered an alternative, it was against their wishes.

“Social Worker informed me I would be going to nursing home if carers couldn’t be able to provide care to which I informed her that I would not in any circumstances move to a nursing home as I did not wish to die...”

3.2 Physical Health



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.

Comments provided by respondents suggest there was confusion about who should be shielding and anxiety about what receiving a shielding letter meant for disabled people.

“we have yet to receive any communication re shielding. Despite one of us being exceptionally high risk...”

“the shielding letter is a death warrant...”



While 96% (390) had not discussed or received correspondence relating to 'do not resuscitate', eleven respondents comments suggested concerns they or someone they care for would not be able to access treatment for existing medical needs and / or would be denied treatment if they contract COVID-19.

"worry about what will happen to me if I get the virus will I get treatment will I be made sign DNR against my wishes..."

"I have found myself increasingly worried about getting sick or injuring myself. Not just of COVID-19 but of anything. I am worried if I get COVID-19 my care is going to be considered less urgent because of pre-existing medical issues..."

Of those who provided comments about DNR or end of life discussions, two explained what this meant for them.

"I was informed if I continue my chemotherapy treatment I would be at risk of not being offered intervention should I contract COVID-19..."

"out of hours Dr told me to talk to my mother about DNR for her. I will not do that..."

Additionally, another respondent explained DNR had been discussed prior to the COVID-19 pandemic.

"I have though when in hospital had a consultant, without speaking to me or my family say because of your disability and weight I see no point in pummelling your chest so I am placing a DNR on you..."

As a result of government measures instructing the public to socially isolate, 56 respondents described how this had led to a decline in their physical health. For people with chronic pain conditions, not being able to exercise or go outdoors for fresh air had led to an increase in symptoms.

"Physical pain due to lack of exercise..."



“Going out to socialise, exercise, and participate in the community is an important part of managing chronic pain for me. The physical movement and mental stimulation provides distraction from pain. When my world gets smaller, as it has done with the current lockdown, the chronic pain I experience grows to fill it...”

Because of problems accessing medication, respondents described a worsening of their health conditions, particularly pain and discomfort.

“I have no meds for three days and apart from the pain which is horrendous I now have to suffer excruciating withdrawal symptoms...”

“I’m in far more pain but doc just giving out medication...”

They also described difficulties accessing routine medical interventions to maintain their physical health.

“District Nurses, no longer attend unless the matter is urgent...”

“GPs are not physically seeing patients. Consultants have cancelled appointments...”

“No longer any assistance from Allied Health professionals...”

3.3 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 suggestive of a decline in mental health.



"I have severe depression and anxiety and have no family support and so have been extremely isolated which has been incredibly difficult and I worry about the long terms consequences of this for my health..."

"My son hates being indoors and I notice it affects his mental health and brings on a lot of obsessive behaviours..."

"I'm quadriplegic and my wife is my carer 24 hrs a day neither of us have left our home since 14 March and its effecting our mental health in a big way..."

Many described feeling fearful and worried about contracting COVID-19 that has placed them under additional emotional stress.

"I am a shielded letter recipient. This has been a very difficult time psychologically and physically. Fear of dying has caused great anxiety to me and my children..."

"Mental health is suffering. Too scared to go out..."

Equally not being able to see or spend time with family and friends lead people to feel lonely, isolated and exacerbated existing mental health difficulties.

"I find that I feel lonelier because I can no longer meet people face to face. There are family members that I cannot see..."

"I suffer with mental health and depression also panic attacks. Not being able to see anyone is making me mad as I miss my friends..."

Changes to normal routine also negatively contributed to emotional wellbeing as it is an essential part of managing health and support needs.

"Not being able to attend adult centre and not being able to carry out my normal daytime routines which have a great affect on my mental health..."
"Having 3 children with ASD who are used to routine e.g. school, drives in car and visits to safe places for exercise (de-load stresses) are struggling with this all being removed..."



“Extremely stressful as due to autism needs routine and support worker every week. No visitors allowed and anxiety and mood is constant stress and anxiety...”

For those who had existing mental health conditions, not being able to access the normal support they receive from their GP or Mental Health Team was additionally problematic.

“Weekly hospital appointments cancelled for mental health...”

“Not being able to see my Mental Health Team...”

3.4 Carers



38% (156) of respondents reported changes or challenges with caring for children or other family members at home relating to disability.

As a result of limited or ceased social care, parents and family members indicated their caring role had greatly increased.

“I have taken over all assistance with care. This involves being available during night and day which is pretty tiring. I’m also assisting with all aspects of personal care preparing food and all kinds of assistance...”

Due to school and daytime activity closures, parents of a child with a disability were struggling to manage the care and support needs of their child, and the demands of working from home.

“I am expected to work from home and care for my daughter who requires supervision round the clock...”

“David needs routine and his routine is completely gone. I am working from home and trying to juggle this with giving him a structured day...”



Carers described how the increases in their caring role were negatively affecting their mental health and emotional wellbeing.

“I am totally exhausted looking after them...”

“Very stressful which adds stress to mental health...”

“High anxiety...”

Respondents who had a disability or long-term health condition also raised concerns about the impact of increased caring roles of loved ones.

“My partner is having to do so much that I’m worried she’ll get exhausted and become ill...”

“It’s harder for my mum to care for both me and my granny...”

“My daughter is also vulnerable with chronic asthma & respiratory disease and I have to depend on her for all my care needs which is very stressful for us both...”

3.5 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 to food and medicine.

There was a maximum of 13% difference between the areas that these respondents lived in indicating slightly more disruption in rural areas. Of the people who provided comments, the main difficulty was in relation to buying food with 75 respondents describing how home deliveries and priority status were particularly problematic.



“I rely on home delivery for groceries and this has been a huge challenge, particularly as I didn’t get a GP letter...”

“Ran out of food today. Managed to get on Tesco's vulnerable list, but won't be delivered for three days...”

“Difficult to get online shopping slot even though I am priority...”

Those who tried to go shopping described the practical challenges this presented.

“Access to shops are hard with the queues...”

“I struggle to carry shopping on crutches...”

“I’m blind so shopping for food and other items is a huge challenge right now with social distancing...”

“I suffer from social anxiety so it is difficult to have to spend so much time queuing at the shops...”

In order to access food, there were increased costs to have food delivered or buy usual items.

“Special diet items not available in supermarket cheaper brands are all gone for most food so shopping is costing a lot more...”

“The local shops do deliver but they have minimum spends which I cannot really afford...”

Thirty-nine respondents explained how accessing medication was problematic for them. This related to delays in receiving medications from pharmacies and supply shortages.

“Slow to get medicines...”

“Medicines frequently out of stock went six days without pain relief...”

Other respondents described initial issues receiving prescriptions but that they had been quickly resolved by their GP Practice or Pharmacy.



“Received a double prescription...”

“Medicine sorted easily my Pharmacy was able to collect my prescriptions and has been delivering them already...”

In response to problems accessing food and medicine, the majority of respondents highlighted that they were dependent on family, or community members to assist them.

“I am depending on my sister for all supplies...”

“I have to rely on strangers to deliver foods and meds...”

“PWD lives on own can’t get food delivery so must go to store but rely on goodwill of others to reach products...”

“I have to depend on family to buy groceries and to pick up prescriptions...”

Collectively, difficulties accessing food and medication had decreased independence and control to be self-reliant.

“Loss of independence and relying on others for basics of living like food and medicine. I have found this loss of independence very challenging...”

“Have to wait so someone can help...”

“The feeling of losing control of the simple things like picking specific groceries...”

Privacy was also a concern when others were providing assistance to buy food or collect medicines / supplies.

“Having to get family to buy groceries means they have to buy sanitary products. It’s embarrassing...”

“Because I cannot go to pharmacy it means family know what my medication is...”



3.6 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.

“Staff and especially key workers have been excellent at explaining “the virus” to my daughter and her housemates...”

“Trust staff have given Easy Read information on Coronavirus. Also on social distancing...”

Comments provided by respondents who had not been able to access information related to delays in receiving information, and that information had been confusing.

“It’s very slow in arriving I got the letter from GP on my 4th week of isolation...”

“Have found a lot of information from government to be contradictory...”

“There’s limited information from organisations, but the advice is somewhat conflicting and vague, due to government guidelines and a lack of clarity on which groups are truly vulnerable...”

Two respondents explained they had difficulty accessing social care information in relation to COVID-19.

“Absolutely not. Issues around Direct Payments are causing so much concern around the legalities of furlough. We have to work it out ourselves despite being really tired...”



“No details have been given to us from the dom. care agency who still call in twice daily at all about their hygiene protocols. The absence of information is concerning so we've asked questions...”

3.7 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 in training or further education had experienced disruption.

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.

“Had to give up work for my caring role...”

“My wife has had to quit to care for our son full time...”

Of those who remained in employment, 22% worked in an industry that placed them at a higher risk of contracting the virus. Positive experiences within employment related to having a supportive employer and being afforded the opportunity to work from home.

“Employer offered working from home early enough, also provided equipment such as monitor and chair to work from home...”

“I work in retail, in a large supermarket, and I was daily in close contact with people because of the department I worked in, thankfully my managers decided it was best that I shield...”



“I’m a primary school teacher. My boss has been very understanding about coming into school and has told me to continue to remote teach and not come into school...”

“Due to my condition it would have been much easier to work from home before this virus started. This was never discussed as an option but now I and others are working from home...”

However, some respondents highlighted working or studying from home was not a long-term option.

“Belfast Met course now remote. Challenging...”

“I have bipolar disorder and a visual impairment and find working from home to be challenging in terms of staying focussed for extended periods...”

“My employer has me working from home which is good for my mental health but comes with increased costs...”

“Working from home has improved fatigue and lowered pain levels. I have more energy. Downside it can be lonely...”

3.8 Social Security Benefits



Only 6% of respondents had experienced difficulties relating to social security benefits. Comments provided primarily related to delays for assessments and new claims.

*“I was due for a PIP renewal but this cannot take place face to face”
“PIP ended on 15 Feb waiting mandatory reconsideration benefit has not been extended...”*



“Made a claim for ESA in February 2020, was going to get an appointment in March but this was stopped due to COVID-19. Still waiting to hear from ESA regarding my claim...”

“I claim for additional housing benefit, I made my claim. but still have not heard back from the Housing Ex...”

3.9 Community Support



Less than half of those who completed the survey (35%) were or had been receiving support from volunteers in their community.

Within comments the following organisations had provided support:

- NOW Project
- Action Ability
- Cedar Foundation
- Headway
- Action on Hearing Loss
- WAVE Trauma Centre
- Chest, Heart & Stroke Society
- Community Relations Forum
- Clanrye Group
- Disability Action NI
- Age NI

Respondents explained the assistance they received had been responsive to their circumstances and highlighted their appreciation of this support.

“The community association have been fantastic, delivered 2 boxes in 6 weeks...they're brilliant...”



“We contacted our local community group at the start as we weren’t sure what was going on and how we would get things...”

“Trust staff has co-ordinated this for us. We are very grateful for their help & support...”

“I apparently was on a list as received a [food] box the first week of shutdown...”

Of those who had not received support from volunteers, their comments suggested difficulties relating to eligibility and delays receiving shielding letters that would confirm their priority status.

“We are not quite disabled enough or vulnerable enough to qualify for support or shielding...”

“Didn’t at the start, was in lockdown for 4weeks without help. Had to pay a fortune for local shop delivery as no online slots...”

“I received leaflets about help collecting medication but because I had not received my letter they said they could not help. They needed letter as proof of my condition and my needs...”

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.

“I call with my elderly neighbour to make sure she has what she needs. And I support my friend who is self-isolating...”

“I co-founded a public online group that is a meeting point for people needing help and people offering help...”

“We are making face shields on our 3D printer”



“I have been sewing cloth face masks for healthcare workers as part of a COVID-19 sewing group...”

Two respondents explained that even though they had to shield, they continued to assist those in need.

“I can't leave the house but try and order extra things in my shopping which I leave outside and a friend collects them for Women's Aid...”

“I run a Foodbank in Belfast and have to do that remotely as I'm at highest risk...”



4.0 Discussion

Our survey sought to evidence what impact COVID-19 has had on disabled people living in NI, and to provide a forum for people to share their lived experiences of the pandemic.

Their responses are specific to the month of April 2020, which began two days after lockdown and shielding measures were brought into effect on 28 March, 2020. Within their responses, challenging circumstances emerge that highlight the sudden and sustained impact COVID-19 has had on their lives. Broadly they reveal the fragility of independence for disabled people and raise questions about the strength of disability rights in the face of such a crisis.

Cumulative Impact

While the survey captured respondents' experiences within key categories, it quickly became evident that many were experiencing multiple challenges at the same time. Throughout the responses we see the cumulative impact of their experiences, such as reduced access to food, medicine, health and social care, and indeed the immediacy of how these impacts occurred at the point of lockdown. It is important to remind ourselves of these combined effects as we examine what our survey respondents told us.

Social Care

35% of respondents indicated the social care support they normally accessed was impacted. For some their support was disrupted due to staff shortages within domiciliary care services, PAs employed via a Direct Payment and closure of day centres. However, for others it stopped on their instruction based on concerns about contracting the virus.



Figures obtained by the BBC News NI, showed that of approximately 24,000 home care packages in place, 4000 of these were suspended during lockdown [\(8\)](#). More data is needed to examine the scope and extent of disruption to social care, however figures from the Office for National Statistics (ONS) indicate during 10 April and 8 May 2020, 3,161 people in England and Wales receiving domiciliary care in the community died. This is more than twice the number of expected deaths for this time of year. Additionally, ONS also reported that social care workers had twice the rate of death due to COVID-19 compared to the general population [\(9\)](#). Similar experiences of social care disruption have also been reported in other areas of the UK, for example, Inclusion Scotland reported 30% of their survey respondents had their social care reduced or stopped [\(10\)](#). In England, following their social care survey, Inclusion London wrote to MPs highlighting disabled people are losing vital social care due to worker sickness, lack of PPE or the need to reduce contact with outside world [\(11\)](#).

Consideration of the mortality rates among disabled people, people with long term health conditions, and those who provide them with assistance in the community would certainly support the decision to limit social care by choice. Yet concerns have been raised that by suspending their care package, some will lose out. In their statement, the Department of Health said most will be reinstated, however reassessment may be necessary if there has been a change in the condition of a recipient or their supporting structures. In response, the Commissioner for Older People, Eddie Lynch called on the Department to prioritise resuming pre-pandemic packages and that people should not ‘lose out’ for taking measures to protect themselves [\(12\)](#).

Prior to the pandemic social care was already under considerable financial pressure. The last decade of austerity has seen substantial cuts to social care funding; only those assessed as having the most severe need are receiving support and for these people the support that they receive is effectively the minimum necessary to enable them to cope [\(13\)](#). Social care is also in the midst of significant structural reform. In 2017, the Expert Advisory Panel Report, ‘Power to People: proposals to reboot adult care and support in NI’ recommended ‘raising the profile of social care, increased emphasis on giving control to service users and supporting family carers and building on existing supports within



communities...improved conditions for the social care workforce, and an appraisal of the true cost of providing care and support' [\(14\)](#).

While progress has been made, it has been admittedly slow. In May, the Health Minister Mr Robin Swann acknowledged how challenging this has been during a ministerial briefing:

“Running health and social care on close to empty for 10 years robbed it of capacity...vital services have been underfunded, short term decisions were preferred over long term planning; difficult choices were ducked; staff were left to feel unappreciated; social care was particularly neglected.” [\(15\)](#)

How social care services resume is unclear. The subsequent Department publication in June 2020, ‘*Rebuilding Health and Social Care Services: Strategic Framework*’ [\(16\)](#), sets out the overarching approaches that will be used to stabilise service recovery, however greater detail has been provided for health and medical needs, with a ‘pending’ gap specific to how local HSC Trusts will support people living in their own homes. These must include building on the existing transformational process and co-production of a recovery plan.

Carers

For many disabled people and people with long-term health conditions, part of their supporting structures are people who provide informal care. Carers who completed our survey described how their role has greatly increased, and they are finding it difficult to manage practically and emotionally. These experiences echo findings from Carers NI, who reported 98,000 people became unpaid carers within a matter of weeks following lockdown [\(17\)](#).

A statement by the Coalition of Carers Organisations NI called on local government to acknowledge the essential role of carers, emphasising they “cannot be expected to ‘carry on’ quietly and in crisis for an unspecified period” [\(18\)](#). Many people wish to care for relatives and loved ones, but without adequate support they are likely to face health and financial challenges.



Pre-lockdown, over 200,000 people in NI already had some form of informal caring role, of which an estimated 30,000 are young carers (19). Across the UK there are around seven million 'informal' or family carers and almost 60% are women. Each year that number is rising with an estimated economic contribution of over £130bn per year. Informal care is an often ignored sector of the economy, but without carers the formal care systems across the UK would be unsustainable (20).

The continued reliance and vital role of unpaid carers has been acknowledged, but as with social care, sector specific guidance from the HSC Trusts detailing how they will continue to support carers in their role is yet to be issued.

Mental Health and Emotional Wellbeing

The impact of COVID-19 on mental health and emotional wellbeing was prominent throughout the survey responses. 72% (294) reported feeling lonely, socially isolated and in some cases, respondents reported an increase in symptoms of existing mental health difficulties. Those already accessing support for their mental health describe reductions and changes in the way they received this. Added to these challenges, there were fears of catching COVID-19 and being denied life-saving treatment.

The World Health Organisation (WHO) anticipated that the pandemic would induce an immense degree of fear, worry and concern for the entire population, but that this would be particularly distinct within certain groups including older people, people with underlying health conditions and care providers. The impact of quarantine on many people's usual activities, routines or livelihoods have resulted in predicted levels of loneliness, depression, harmful alcohol and drug use, and self-harm or suicidal behaviour (21).

A UK wide study involving Queen's University Belfast has explored the psychological impact of lockdown and the COVID-19 pandemic on people here. The survey of over 2,500 people of which 470 were from NI, one third have been found to meet the criteria for anxiety (30%) and depression (33%), and one in five (20%) meet the criteria for COVID-19 related Post Traumatic Stress Disorder due to the current pandemic (22).



The existing challenges regarding the mental health and wellbeing of the local population are well documented, including the impact of living in a post conflict society. Compared to the rest of the UK, there are 20-25% higher levels of mental health illness, and around 1 in 5 adults are reported to have a diagnosable mental health condition at any given time. There are significantly higher levels of depression, higher antidepressant prescription rates, and higher incidences of self-harm. NI also has the highest rate of suicide in the UK [\(23\)](#).

For people who are living with a disability, a long-term health condition and/or are informal carers, the risk of developing a mental health condition is greatly increased, in part because of social isolation. Sustained periods of staying at home, having no access to services or community involvement, and limited or no communication with friends, family, and acquaintances can have a devastating effect. Depression, poor sleep quality, impaired executive function, accelerated cognitive decline, poor cardiovascular function and impaired immunity have been directly linked to social isolation, which subsequently has been shown to increase the risk of premature death [\(24\)](#).

In response to the mental health needs of the population, and the impact of COVID-19, the Department of Health announced at the end of April 2020 that it had begun the process of appointing a Mental Health Champion [\(25\)](#); subsequently, the COVID-19 Mental Health Response Plan was published and in June, Professor Siobhan O'Neill was appointed interim Mental Health Champion. These swift actions are welcomed measures but how effective they can be is not yet clear, particularly given the NI budget for mental health services is already the lowest in the UK, despite having the highest levels of mental health needs [\(26\)](#).



Physical Health

A decline in physical health was also reported by our survey respondents; some associated this with exercise limitations, problems accessing medication and restrictions on routine health or medical appointments. Respondents additionally linked their physical symptoms to a decline in their mental health. Fears of catching COVID-19, and what this might mean for people with existing health conditions seeking treatment, were also contributing factors.

Since the onset of the pandemic, hospital referrals, admissions and attendance at Accident and Emergency Departments have significantly dropped, prompting calls for people not to ignore emerging symptoms [\(27\)](#). However, this has been problematic for people with disabilities and long-term health conditions for a number of reasons. Firstly, concerns about catching COVID-19 whilst in hospital, particularly for those advised to shield; confusion about who should be shielding, and lastly concerns about being denied treatment and viewed as less of a medical priority. While almost all respondents had not received correspondence relating to 'Do Not Resuscitate' or end of life decisions, fears relating to this were evident. Why these fears were so potent are undoubtedly related to the publication of the National Institute for Clinical Excellence (NICE) COVID-19 guideline for critical care [\(28\)](#).

The guidelines specify which patients will qualify for admission to hospital and referral to critical care, should their COVID-19 illness require this, and which patients will not be offered such treatment. The original version of the guideline stated that on admission to hospital, an assessment was to be conducted for every adult against a nine-point Clinical Frailty Scale for Frailty Assessment [\(29\)](#).

Many people living with a disability or long-term health condition and their representatives immediately raised serious concerns about the suitability of the CFS and how it would put them at a disadvantage when decisions were made about admission to critical care. In response to the initiation of a Judicial Review challenge, at the end of March NICE updated their guidelines for clinicians to use an 'individualised assessment' of frailty for the under 65s, including younger adults with autism or a learning disability,



without assuming that a long-term disability or care requirement is a reason not to offer treatment [\(29\)](#).

Despite these amendments, no further action has been taken to consider or address the emotional distress and confusion this has resulted in; however, it is important to reflect on the enduring impact this has had. Our survey respondents describe immense fear and anxiety about how they would be assessed in any medical context which may mean they are less likely to maintain existing or seek new medical interventions essential for their health. It also raises questions about the strength of legal and ethical frameworks that surround the context of end-of-life decisions.

Accessing Information

Of 330 respondents, 225 (68%) said that they found health and other public information to be accessible to them. 54 (16%) said they did not find it accessible, and 51 (16%) said they did not know whether it was accessible or not.

Of those who had difficulty, they cited a lack of clarity and consistency as a problem. Information could be slow to arrive and, for some, in an inaccessible format. The dangers around accessing information for disabled people are two-fold: disabled people are less likely to be able to access the information than the general population, and, depending on conditions and impairments, they are less likely to be able to understand and/or follow it physically [\(30\)](#). This leaves them more vulnerable to infection and illness, as well as more likely to further the transmission of the virus to other people.

Dr Bronagh Byrne of Queen's University said the pandemic is "*further alienating*" disabled people from society in a number of ways, including not having sign language interpreters initially available in daily briefings to disseminate information about social distancing and preventive measures against COVID-19 to the D/deaf community [\(31\)](#). This issue must be considered for other groups, including those who are blind or partially sighted. Easy-read information must be readily available for those with learning disabilities.



When it comes to finding information about specific conditions and impairments in relation to COVID-19, 190 (59%) of 322 respondents said they had no problems. 80 (25%) said they were unable to access information about their specific condition or impairment, and 52 (16%) did not know what information was available.

Comments reveal that some are relying on charities for support and information about specific conditions or impairments. People with rare conditions or impairments may struggle more than others to find information. Specialist clinics could undertake a more pro-active approach in contacting their out-patients to advise them or answer any questions they might have.

Accessing Food and Medicine

More than half of our survey respondents reported experiencing difficulties accessing food and medicine. Supermarkets and grocery shops saw a surge in demand even before lockdown was introduced. The problems this created were widely reported, particularly for the elderly, people with disabilities and long-term health conditions, and key workers.

Similar experiences have been reported across the UK., For example, Scope have found most queries they receive relate to access to food and essentials. As with our survey respondents, they reported some disabled people are ineligible for additional support set up by the government because their condition or impairment means they are not classified as “clinically extremely vulnerable”. This is leaving a lot of disabled people not included in this category, who previously relied on online shopping deliveries before the outbreak, are now finding that their regular slots are no longer available [\(32\)](#). The introduction of priority status measures sought to address these issues but for people without proof of their priority status via a shielding letter this was problematic.



‘Not quite disabled enough’

Comments suggest that there is some confusion among respondents as to what qualifies a person for support, leaving people uncertain of where to turn. In England, elderly and vulnerable people could get priority for slots with major supermarkets through an online system, although reporting shows that disabled people were being omitted from lists of vulnerable people due to “highly selective criteria” [\(33\)](#). In NI, during this time there was no such system, as the Department of Communities said it was too complex to be replicated here [\(34\)](#). The department said it would provide food parcels to those most in need, with 10,000 set to go out to those who have been told to shield (as of 7 April). There was a delay in sending shielding letters to 40,000 people identified by the government as very vulnerable to infection [\(35\)](#).

Reports reveal differences between government list and GP records; one doctor talks about GPs using discretion for some and others being in a “grey area” in terms of shielding [\(35\)](#). These factors could account for the low number of respondents (96) who had received a shielding letter at the time of our survey and the confusion as to who should have received one and what support it meant they could access.

Social distancing restrictions put in place in shops are also causing difficulties for some disabled people, such as those who need someone to support them with their shopping. Disabled people are being asked to get friends, family or members of their community to help with shopping, but this is not always possible, particularly for people without an existing support network. The Research Institute for Disabled Consumers reported 45% of their research participants feel supermarkets are performing poorly or very poorly with a large proportion of people are struggling to get shopping. Additionally, when asked how concerned people were if the crisis lasted more than three months, 38% were very concerned about the supply of food [\(36\)](#).

Where support has been offered, it has sometimes been inconsistent or unsuitable. Food deliveries co-ordinated by government agencies have not always taken dietary requirements into account, such as gluten or lactose intolerance, and whether disabled people can physically eat what is being provided to them.



Support from Community Volunteers

When asked whether they had been in receipt of any help from volunteers in the community, 35% of those who responded said they had, while 65% had not. Of the respondents receiving support, 16% had received help from the local community and 12% had been supported by their neighbours. Research conducted by disAbility Cornwall & Isles of Scilly (DCIS) found that three-quarters (74%) of disabled people were receiving no support from charities, the NHS or their local community [\(37\)](#). This could suggest that NI has a more efficient network in the community and voluntary sector to distribute the help needed, or perhaps has more robust family structures to address need.

Some respondents explained that they did not want help, because they did not want to risk exposing volunteers or themselves to the virus. Some may be reluctant to use voluntary support but could be more receptive to organised government-led intervention if it is perceived as having a greater level of safety, being more 'official' and is not risking the health of unpaid, good-natured people.

Supporting the Community

When asked if they were participating in supporting others in their community, 65% of respondents said they were. Comments indicate that this ranges from donating money and food, providing emotional support and signposting over the phone and internet, to creating facemasks and co-ordinating support in the community. Data from ONS reported a similar figure, with two-thirds of disabled people (65%) checking on neighbours who might need help at least once [\(38\)](#). This demonstrates that disabled people are vital and active members of the community; in fact, ONS data reveals they are just as likely (if not slightly more) to support their communities than non-disabled people (63% of whom say they have checked on neighbours at least once).



Additional Costs: Heating and Eating

Some respondents mention the additional costs they are facing during the coronavirus pandemic, such as an increase in energy use while working or shielding at home all day, paying extra for food deliveries and shopping at smaller, more expensive local stores. Research shows that convenience stores tend to charge anywhere between 5-7% more on grocery prices [\(39\)](#), adding to disabled people's cost of living.

Additionally, some disabled people are relying on friends, family, neighbours or volunteers to shop for them, making it more difficult for them to budget if the person helping them shops at a more expensive store. Research shows that this increase in the cost of living has been a global phenomenon for disabled people during the pandemic, as 91% of disabled people surveyed in Australia reported increased living expenses, largely in the area of food and groceries [\(40\)](#).

The cost of living has risen for everyone during the pandemic, not just disabled people. The ONS reports 1 in 4 people had already been affected financially by the pandemic by late March/early April, and that a typical shopping basket costs 4.4% more than just before lockdown measures began in March [\(41\)](#).

The UK government has increased the weekly rate of Universal Credit by £20 to counteract the costs of the pandemic, but disabled people who receive employment and support allowance (ESA), a benefit that pre-dates universal credit, will see no such increase [\(42\)](#). Prior to the COVID-19 pandemic, disabled people already faced extra costs of £583 a month related to their impairment or condition on average [\(32\)](#). Given the evidence that disabled people are facing even greater increases to living expenses at this time, they risk falling further behind the general population financially.



Accessing Benefits: Application and Appeals Process

When asked “*Has the COVID-19 pandemic had an impact on accessing the social security benefits you or the person you support/care for need?*”, 68% report that they have not experienced problems around receiving benefits. However, 22% say they have had problems accessing benefits or anticipate they will have problems in the future. 9 people specify being in the process of applying for benefits or appealing a decision and having that process delayed by the pandemic, especially since face-to-face assessments have been delayed indefinitely.

Nationally, 166,630 Personal Independence Payment (PIP) claimants were awaiting assessment as of 27 April; as of 4 May, 101,910 people were waiting on ESA claims [\(43\)](#). In NI, Minister for Communities Deirdre Hargey said, in addition to face-to-face assessments being suspended, benefit claimants also faced long delays on telephone calls to claim PIP or ESA due to staff being either absent or redirected to handle the surge in Universal Credit applications [\(44\)](#).

In addition to the anxiety created by COVID-19, two comments reveal that there is still an underlying residual fear for some around a benefits system transformed by years of austerity. This means that some disabled people are experiencing greater levels of anxiety in an already anxiety-ridden process at a time when the nation is in the grip of a crisis.

Access to Cash

Some respondents report difficulty accessing cash, particularly if their benefits are deposited into a post office account. This is problematic, given that cash is fundamental to disabled people’s ability to access goods and services through friends, family, neighbours or volunteers. Research by shows that 1 in 5 people said they have been helping someone outside of their immediate household to access goods or services during the pandemic, and the majority had been repaid in cash [\(45\)](#).



Even if they can access cash, the same research reveals that 1 in 10 “were refused by shops when trying to pay with cash – at a time when only shops selling essential goods were open”. This reluctance to use cash has been based on conflicting information over the safety of using it during the pandemic – early reports in the media suggested cash could carry the virus, a claim later refuted by WHO [\(46\)](#).

While the Post Office has made several services available to all banks, building societies and credit unions in NI, it is the choice of each individual service provider whether they use these services to make cash available to their customers [\(47\)](#). This could lead to an uneven service provision to disabled people relying on cash across the country.

Job retention and COVID-19

In total 4% of our survey respondents who are disabled or have a long-term health condition lost their jobs in April as a result of the crisis caused by the spread of COVID-19. This is in line with the national trend for all workers: approximately 3% lost their jobs across the UK in the same period [\(48\)](#).

While the rate of job losses among disabled people and those with long-term health conditions is in line with the UK average for all workers since the start of the crisis, it should be noted that disabled people in Northern Ireland are disproportionately more likely to be unemployed in the first instance. The pre-COVID-19 employment rates for disabled people in England and Scotland were 54% and 47% respectively. However, for NI the corresponding rate of employment among disabled people was only 35% [\(49\)](#). Therefore, the rate of increase in joblessness for disabled people in NI, while increasing at the same rate as the overall UK figure for all workers, is taking effect on an already depleted pool of employed people, having a disproportionate effect on the disabled community.

Challenges also existed for those who provide support for disabled people or those with long-term health conditions in gaining and/or retaining paid employment pre-COVID-19, including the inflexibility of the formal care system and sudden changes in circumstances [\(50\)](#). As our research shows, two respondents indicated that they or a family member have



already given up their jobs due to increased caring responsibilities in the face of COVID-19.

Data on the impact of COVID-19 on levels of unemployment is still at an early stage. The UK government's furlough scheme has mitigated some of the damage, but there is broad agreement that the UK economy is set to suffer one of the most severe contractions in its history. When the furlough scheme ends, experts predict a sharp increase in job losses [\(51\)](#).

To understand how this might affect disabled people in the future, it is useful to look at the last recession following the financial crash in 2007. [disability@work](#) claims that, in the UK, *"there is little evidence that disabled people were proportionately more likely than non-disabled people to lose their jobs"* [\(52\)](#). So far, this is concordant with the results of our research, that disabled people are reporting losing employment at the same rate as the general population.

If the financial crash of 2007 did not affect disabled people disproportionately in terms of job losses, they did report a worsening of conditions beyond those experienced by non-disabled people, such as wage freezes, increased workload, and restricted access to training. This shows that disabled people can expect inequitable treatment from employers during economic hardship and that *"organisational responses to downturns affecting employment terms and conditions form an important source of inequality at work"*, widening the pre-existing pay and job satisfaction gaps [\(52\)](#).

While research indicates that disabled people may not be more likely to lose employment than the general population, it is likely that COVID-19 will be detrimental to closing the disability employment gap, which we know is much wider in NI than the rest of the UK. As the economy shrinks and more people end up out of work, disabled people find themselves in an ever more crowded labour market. Perhaps locked out of employment for years by systemic stigma and prejudice, the challenge for unemployed disabled people before the pandemic becomes unassailable: *"as the employed become unemployed, the already unemployed are pushed to the back of the queue, further away from employment"* [\(53\)](#).



Safety at Work

Disabled people or those with long-term health conditions face greater challenges maintaining their safety in the workplace during the coronavirus pandemic. Some have compromised immune systems due to their impairments or conditions, or possibly because of the medication they take. Those with mental health conditions have their symptoms exacerbated by greater levels of stress and anxiety, as nearly 9 in 10 (86.3%) of disabled people reported they were "very worried" or "somewhat worried" about the effect that the pandemic was having on their lives in April 2020, around the same time our survey was conducted [\(54\)](#).

Over a fifth (79) of those who responded to the question (361) said they, or the person that they supported, worked in a job that put them at risk of coming into contact with the virus. Some comments suggest that disabled people fear contracting the virus through family members who are keyworkers. Those who commented have generally positive things to say about their experience with employment so far, stating that employers seem understanding of the need for some disabled people to shield during the height of the pandemic. However, as discussed previously, the real economic impact of COVID-19 and the lockdown has yet to be realised. In the grip of a recession, accommodating disabled people's safety at work (or hiring them in the first place) may start to look like an unaffordable luxury for some employers.

Working from Home

Respondents' comments suggest that the move towards working from home where possible has been a largely positive change for disabled people. They say that working from home has never been considered an option for them by their employers, but now they are being accommodated due to the pandemic and the general population's need to work from home. Some report a reduction in fatigue and pain levels and feeling less stigmatised for needing to work at home due to their disability or long-term health condition.



Disabled people face greater challenges when it comes to accessing the workplace. It can be more difficult for them to commute, and workspaces are rarely fully accessible. People with energy-limiting impairments or conditions may need to work in short bursts followed by rest periods, which may not be possible in a busy workplace.

Access to working from home has been a long-standing issue for disabled people. Some disabled people believe that *“the only barrier [to working from home] was that their employer would not trust that they were working as hard as if they were in work”* [\(55\)](#). However, it has been argued that it could open up employment for some of those who have been denied an opportunity thus far, and boost the wellbeing and performance of those who struggle to make it to work on a daily basis in an inaccessible world. According to Eileen Hopkins, Executive Director of Ai-Media, *“COVID-19 is to some extent levelling the playing field between disabled and non-disabled employees”* [\(56\)](#).

In fact, employers are now turning to the disabled community for advice on overcoming the challenges of home working as the landscape of employment changes. They have already learned to deal with the problems thrown up by the pandemic, such as *“restrictions, challenges and health anxieties”* as *“part and parcel of daily life”* [\(57\)](#). Disabled people are the experts of their own experience and, as our survey shows, they know they need support in terms of clear and regular communication with employers and colleagues, and the provision of equipment to do their job to the best of their abilities. These are valuable lessons for all employers and employees to take on board.

Working from home does not suit the needs of all disabled people or those with long-term health conditions. It can be isolating, and distractions can make it difficult to concentrate. Those with depressive or attention-deficit disorders may need a workplace environment to help them focus or make contact with other people if they lead an otherwise solitary life [\(55\)](#).

Research shows that disabled people are concerned that they could be confined to working at home, in what is described as “a ‘lazy’ solution for employers” [\(55\)](#). If this were to happen, it could reduce the visibility of disabled people in public life, exclude them from certain job roles and see them passed over for career enhancing opportunities. What disabled



people want most of all is the flexibility to choose whether they want to work at home or an outside workplace.

Sickness Absence

Some respondents to our survey feel more supported than others, and some fear support may not last in the event of sickness. This anxiety is informed by the fact that, even prior to COVID-19, “UK employers are particularly likely to be exercised by levels of sickness absence” [\(58\)](#). Disabled people and those with long-term health conditions can be more likely to need sickness absence and, with increasing levels of sickness and the potential need to quarantine in the general population due to COVID-19, disabled people could suffer more in terms of employment:

“Any attempts by employers to bear down on the costs of sickness absence may well have a disproportionate effect on disabled employees and contribute to the disability employment gap by causing them to leave their jobs.” [\(58\)](#)

In view of the grim economic forecasts in the wake of the pandemic, employers could be more desperate to cut costs and see disabled people as a liability for their business. Employers could be even less likely to recruit disabled people in the future for fear of a second or even multiple waves of infections, in which disabled people may have to return to lockdown more readily than a non-disabled employee.

Disruption to Training & Further Education

When asked whether their training or further education had been affected by the coronavirus pandemic, 73 (22%) of the 338 respondents said either it has, or they expect it to be in the future. Statistics reveal that disabled students made up approximately 32% of the young people who took part in the Training for Success programme, which provides vocational training for young people aged 16 to 24 years old, in the years between 2013 to 2017 [\(59\)](#). Given that 21% of people in NI identify as disabled [\(60\)](#), this is a significant over representation.



Exams for vocational training were cancelled in early April, and all face-to-face instruction moved online where possible [\(61\)](#). Our survey shows that remote learning has proven difficult for some respondents due to a lack of equipment or feelings of isolation and uncertainty. Much of this uncertainty revolves around how exams will resume, as the range within vocational training means students could be studying topics as diverse as beauty therapy, catering and warehousing, which require very different methods of assessment. Conducting exams in an equitable way will be challenging, as some subjects will be more easily assessed than others under social distancing rules.

A delay in assessments for certain subjects may disrupt the future plans of students hoping to enrol in further study. Disabled students who want to attend Belfast Metropolitan College this year are already finding that enrolment has been disrupted due to COVID-19, with only 66 places for 166 people wishing to study at its Centre for Supported Learning being awarded through a “*randomised selection process*” [\(62\)](#). The randomised nature of the selection process will deny these students the opportunity of a face-to-face interview. One mother summed up the situation for her disabled daughter:

“[T]he uncertainty posed by coronavirus and the final school year finishing in March... only heightened the fear and uncertainty for these young adults, who at this point in their lives have so few choices available to them to advance their essential life skills for independence.” [\(62\)](#)

Students wishing to join the world of work post-training will be joining the crowded labour market, where the post-COVID-19 recession exacerbates the same prejudices and stigma that maintains the disability employment gap for disabled people with little to no recent job history [\(52, 53, 55\)](#).



5.0 Limitations

The following limitations of the survey have been identified:

1. Timeframe: As the survey was available for one month only, it is difficult to determine the longevity of respondents' experiences. While the findings do evidence a prominent period at the initial stages of the pandemic, further data would be necessary to understand the timeframe of these experiences.
2. During the analysis and write-up of the survey report, numerous reports and governmental publications were issued. As such, publications accessed were time limited until 30 June 2020. We recognise that as further evidence emerges, this will impact our overall discussion and recommendations.



6.0 Recommendations

Disability Strategy

We now respectfully call upon the Minister for Communities to 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. The failures of previous strategies have arisen for a variety of reasons, however many in the disabled community felt there was a failure to meaningfully involve them or prioritise it. 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.

Data Collection and Sharing

We respectfully call upon the Minister for Finance to ringfence appropriate resource for NISRA to enable better availability of historic and future disaggregated data in relation to disability in Northern Ireland.



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 we should have a better understanding of those with a disability who make up 1 in 5 of the entire population.

Reforming Social Care

We respectfully call upon the Minister for Health to produce as a matter of urgency a timetable for moving reform of adult social care forward in Northern Ireland.

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

We respectfully call upon the Minister for Health to now 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

The NI Executive must now 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 role that carers play. They are effectively a hidden pillar in our health and social care system. We are 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

We are calling upon large supermarkets to commit to reviewing with disabled people and Government how they approached the issue of prioritisation of food delivery for disabled customers during COVID-19 in NI.

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-19 are at all times done in partnership with disabled people and their organisations.

The evidence before us has demonstrated the importance of existing, specialised programmes of support. Ensuring job opportunities, job retention and job progression in the new COVID landscape for disabled people 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

We are calling on Government to recognise disabled people as not only passive participants 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 already faced substantial additional barriers to exploring and participating in volunteering opportunities in NI. In the decade ahead, it is now more critical than ever that these barriers are removed. The contribution of so many disabled volunteers during the pandemic was a significant indicator of just how much our community has to offer through volunteering.

Support for DPOs and the wider Sector

We are calling upon the NI Executive to work with disabled people in identifying the long-term support needs for their organisations.

It is critical that the mechanisms we use 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

We are calling upon the NI Executive to 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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8.0 Appendices

Appendix 1: Disability Action NI online survey - COVID-19 The impact on disabled people in Northern Ireland (April 2020)

Covid-19 is affecting us all. The last few weeks have seen tremendous changes across our society here in Northern Ireland and around the globe.

As disabled people we are not just at risk from the virus. As a community, we continue to be at risk from the actions of others who take decisions about us in our absence.

Keeping up with developments in such a fast paced environment can be both confusing and frightening. Yet, as a community we have come together like never before. Disabled people are world leaders in adapting, innovating and overcoming. Our voices matter.

Why we are doing this survey?

We want to make our voice heard. We want policy and decision-makers to know what is really happening to disabled people on the ground, and what changes are needed. We need information from you to do this.

This survey is anonymous. You should not provide any personal or identifying information about yourself or anyone else. This includes things like people's names. If you do include this it will not be stored, and we will not use it.

Who is this survey for?

We particularly want to hear from disabled people, or those who support a disabled person. You do not need to fill out all the questions, just those that matter to you, and Section 1 About you.

We are interested in hearing from you about what has happened to you since the start of Covid-19 changes. We want to hear about issues and barriers you have faced, and about any positive experiences.

Thank you in advance for completing the survey.

Section 1 - About you

1. Are you filling this survey in for yourself or on behalf of someone you support/care for?

- I am filling this survey in for myself
- I am filling this survey in on behalf of someone I support/care for
- I am filling this survey in for myself and the person I support/care for as we are both disabled people

2. Do you consider yourself any of the following? Please tick all that apply.

- A disabled person
- A person with a long-term health condition
- A disabled person who also cares for/supports a disabled person
- A non-disabled person, but I care for/support a disabled person
- A non-disabled person

Other (please specify)

3. What county do you live in?

- Antrim
- Armagh
- Derry~Londonderry
- Down
- Fermanagh
- Tyrone

4. Please tell us what kind of area you live in

- A city
- A town
- A suburban area or village
- In the countryside
- On an island

5. Do you or the person you support have a health condition that puts you/them at high risk from Covid-19?

- Yes
- No
- Don't know

6. If you were expecting to receive a 'shielding letter' from your doctor, has it arrived?

- Yes
- No

7. Has any health or social care professional spoken or written to you about 'Do Not Resuscitate' or 'End of life Decisions' in relation to Covid-19?

- Yes - I had requested this information
- Yes - But I hadn't requested this information
- No
- If yes, please briefly tell us more about this

Section 2 - What impact has Covid-19 had on you?**Support and Care**

8. Has Covid-19 had an impact on the social care support you normally get?

This includes things like getting less support or no support at all, changes to the support you get, charging for care. It covers care at home, support from a Personal Assistant or other forms of self-directed support, care in a nursing or residential home, respite care, support to leave hospital.

- Yes
- No
- Don't know
- Not yet, but might in the future

Please briefly tell us more about this

9. Are you, or the person that you support/care for, experiencing any changes or challenges with caring for children or other family members at home that relate to disability?

- Yes
- No
- Don't know
- Not yet, but might in the future

Please briefly tell us more about this

Access to food and medicine

10. Has the Covid-19 pandemic had an impact on getting the food or medicine that you or the person you support/care for needs?

- Yes
- No
- Don't know
- Not yet, but might in the future

Please briefly tell us more about this

Employment

11. Have you lost your job as a result of Covid-19?

- Yes
- No
- Not yet, but might in the future
- Please briefly tell us more about this

12. Do you, or the person you support/care for, work in a job that puts you/them at risk of coming into contact with the virus?

- Yes
- No
- Don't know
- Not yet, but might in the future
- Please briefly tell us more about this (for example, tell us if you are a key worker)

13. Do you, or the person that you support/care for, have any worries or more positive experiences about your job?

This includes things like working from home, being paid if you can't attend work, getting information from your employer.

- Yes
- No
- Don't know
- Not yet, but might in the future
- Please briefly tell us more about this

Education and Training

14. Has your Training or Further Education been affected?

- Yes
- No
- Not yet, but might in the future
- Please briefly tell us more about this

Benefits and Social Security

15. Has the Covid-19 pandemic had an impact on accessing the social security benefits you or the person you support/care for need?

- Yes
- No
- Don't know
- Not yet, but might in the future
- Please briefly tell us more about

Social distancing and being isolated

We have all been told to try to reduce social interaction between people in order to reduce the spread of Covid-19. This is called social distancing. This means we have been told to stay at home; to only go outside for food, health reasons or work (but only if you can't work from home); to only take one form of exercise a day alone or with members of your household; to stay 2 metres away from other people at all times when out of the house and to wash your hands as soon as you get home.

Those at very high risk from Covid-19 have been told to self-isolate. This means we have not to leave our homes at all and have to minimise all non-essential contact with other members of our household.

16. Please tell us briefly about the impact being isolated at home is having on you or the person that you support or care for.

For example, not being able to see friends or family and not being able to go out for exercise.

Accessible information

17. Is all health and other public information about Covid-19 accessible to you or the person you support/care for?

- Yes
- No
- Don't know
- Please briefly tell us more about this

18. Can you or the person you support/care for, find accessible information about Covid-19 and your/their impairment?

- Yes
- No
- Don't know
- Please briefly tell us more about this

Support in your community

19. Are you or the person you support/care for, getting support from volunteers?

- Local community
- Neighbours
- The Council
- NHS
- Red Cross
- Somewhere else. Please say where from in the box below
- Not yet, but I have asked for support
- No, I am not getting support from volunteers

Please briefly tell us more about this

20. Have you been participating in supporting others in your community? If so, tell us how.

Finally

21. Are things harder for you at the moment because of any of the following (tick all that apply):

- You're a disabled woman
- You're a disabled man
- You're a disabled person on a low income
- You're a disabled gay, lesbian or bisexual person
- You're a disabled younger person
- You're a disabled older person
- You're a disabled parent or pregnant woman
- You're a disabled religious person
- You're a disabled transgender person
- You're a disabled person from an ethnic minority
- You're a disabled married person
- Please briefly tell us more about this

22. Is there anything else you would like to tell us about the impact that Covid-19 is having on you, or the person you support/care for, on your household or on your community.



Covid-19 - The impact on disabled people in Northern Ireland

Covid-19 - The impact on disabled people in Northern Ireland

Thank you for taking the time to complete this survey. It will really help us to get the best help for disabled people and the people who support us.

If you need advice about Covid-19 as a disabled person please go to our [COVID-19 page on our website](#). Alternatively you can contact Disability Action HQ on 028 9029 7880 (between 9.30am – 4pm) or email hq@disabilityaction.org



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Textphone: 028 9029 7882
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