

The impact of Covid-19 on people with a learning disability in Northern Ireland: Implications for policy and practice.

Appendix 3: The experiences of people with learning disability in Northern Ireland.

This appendix presents the findings from the surveys undertaken in Northern Ireland for Cohort 1 (interviews with people with learning disabilities) and Cohort 2 (carer reports).

The second section presents the main themes which featured in the comments made by participants in the surveys but they have been augmented by interviews which the NI partners undertook with people with learning disabilities known to them.

Section 1: Survey findings

Participants

Information was obtained on 189 persons with learning disabilities living across Northern Ireland. Table 3.1 summarises the characteristics of people with learning disabilities who enrolled in the study at Wave 1 in both cohorts. Their characteristics are broadly similar to those of the national sample reported in Appendix 1.

Table 2: The characteristics of participants with learning disabilities in the study

Demographic variables	Cohort 1 (N=127) (interviews with adults with learning disabilities)	Cohort 2 (N=62) (reports by family carers and support workers)
Age 16-44 45+	n=85 (67.5%) n=41 (32.5%)	n=40 (72.7%) n=15 (27.3%)
Gender Male Female	n=62 (50.0%) n=62(50.5%)	n=33 (58.9%) n=23 (41.1%)
Ethnicity White All other groups	White n=127 (100.0%) Other ethnic group n=0	White n=60 (98.4%) Other n=1 (1.6%)
Person with Profound Multiple Learning Disabilities (PMLD) Yes Not sure/No	<i>Data not collected</i>	n=21 (42.8%) n=28 (57.2%)
Down syndrome Yes No	n=15 (12.2%) n=107(87.8%)	n=15 (24.2%) n=47 (75.8%)

Living situation		
Living with family	n=64 (50.1%)	n=41 (66.1%)
Living alone/with partner	n=32 (25.4%)	n=5 (8.1%)
Living with other people with learning disabilities	n=30 (23.8%)	n=16 (25.8%)

Note: Missing data is omitted, and percentages are calculated on responses given.

As is usual with longitudinal studies, the number of participants in Cohort 1 decreased in Northern Ireland from 127 to 107 (wave 2) and 80 (wave 3). In Cohort 2 the respective number of responses dropped from 62 to 34 (wave 2) and 35 (wave 3). Mostly this was due to participants in Cohort 1 being unavailable after three attempts had been made to contact them but other reasons was because of bereavements and illnesses. The short time interval between waves may also have been a factor as respondents in both cohorts may feel they had nothing new to report.

Findings

The findings reported here are mainly drawn from Cohort 1 unless the pattern of responses was different in Cohort 2, that is those with more severe forms of disability.

Experiences of Covid-19

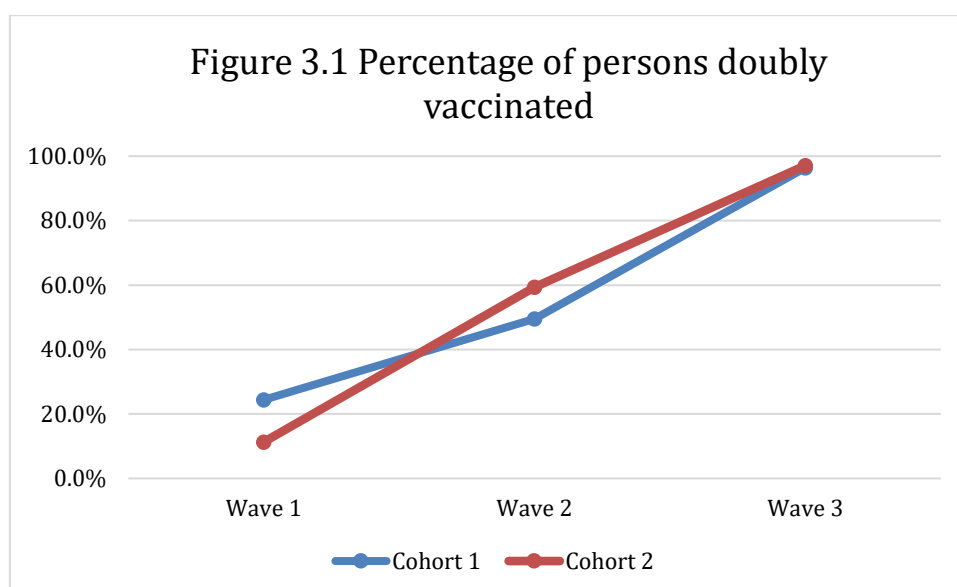
In Wave 1, two of the 189 (1.1%) NI participants had Covid-19 and one person had been hospitalised (0.5%). In all over one fifth had been tested and found to be negative (n=39: 20.6%). However four persons (3%) in Cohort 1 thought they may have had Covid-19 but had not been tested. Nine people lived with some-one who had Covid-19.

When asked about getting good information about Covid-19, at Wave 1, 73% said they had and this rose to 79.4% at Wave 2 and to 85.7% at Wave 3. Most of their information came from the television (78.7% mentions) followed by support workers (35.4%) and social media (21.3%). The government website was rarely mentioned (9.4%). However, 27.6% claimed to have downloaded the Stop Covid NI App with 19.7% stating they had used it when out.

Around 90% reported wearing a mask when outside the home at Wave 1 and this continued in later waves.

Figure 3.1 reports the percentage of persons with learning disabilities reported to have been doubly vaccinated at each wave. This increased during 2021 and by July nearly all persons had been doubly vaccinated; a higher proportion than the general NI population.

The vaccination rates were higher than those who had received the flu vaccination which were 66.9% in 2020 and 64.1% in 2021. This may reflect the difficulties in accessing GP services.



Worries about Covid-19

Around half of the respondents (n=62: 49.2%) had a condition that made them worry about catching coronavirus. The most common ones were asthma, diabetes and heart conditions. Just over one quarter had shielded (n=34:26.8%).

Table 3.2 summarises the worries that participants had in relation to Covid-19. At Wave 1, the biggest worries were their family and friends catching Covid-19, missing out on day-time activities and giving the infection to someone else. The worry that they might catch Covid-19 tended to be rated as a little worry.

In later waves the extent of their worries had reduced with relatively little change between waves 2 and 3. The biggest worry remained that family and friends might catch Covid-19

Table 3.2: The number and percentage of people ratings their worries at wave 1 (n=127); wave 2 (n=101) and wave 3 (n=80)

Worries	Not at all	A little worry	A big worry	Does not apply/missing
I'm worried that family and friends will catch coronavirus	26 (20.8%)	41 (32.8%)	58 (46.4%)	2 (1.6%)
	31 (30.1%)	45 (43.7%)	26 (25.2%)	1 (1.0%)
	19 (24.7%)	34 (44.2%)	24 (31.2%)	0
I'm worried about missing school/college/work	19 (15.1%)	35 (27.8%)	57 (45.2%)	15 (11.9%)
	38 (36.9%)	26 (25.2%)	25 (24.3%)	14 (13.6%)
	28 (36.4%)	17 (22.1%)	15 (19.5%)	17 (22.1%)
I'm worried I might give the infection to someone else.	38 (30.2%)	32 (25.4%)	53 (42.1%)	4 (3.2%)
	47 (45.6%)	33 (32.0%)	22 (21.4%)	1 (1.0%)
	31 (40.8%)	34 (44.7%)	10 (13.2%)	1 (1.3%)
I'm worried that I will catch coronavirus	36 (28.3%)	56 (44.1%)	34 (26.8%)	1 (0.8%)
	47 (46.1%)	41 (40.2%)	13 (12.7%)	1 (1.0%)
	32 (42.1%)	32 (42.1%)	12 (15.8%)	0

I'm worried about the long-term effect this will have on me getting a job	28 (22.2%) 29 (28.7%) 23 (29.9%)	25 (19.8%) 15 (14.9%) 7 (9.1%)	29 (23.0%) 13 (12.9%) 9 (11.7%)	44 (34.9%) 44 (43.6%) 38 (49.4%)
I'm worried to leave my home right now.	51 (40.5%) 67 (65.0%) 53 (68.8%)	46 (36.5%) 27 (26.2%) 13 (16.9%)	25 (19.8%) 9 (8.7%) 10 (13.0%)	5 (3.9%) 0 1 (1.3%)
I'm worried about the amount of money coming in.	73 (57.9%) 57 (56.4%) 49 (64.5%)	25 (19.7%) 9 (8.9%) 6 (7.9%)	11 (8.7%) 7 (6.9%) 2 (2.6%)	17 (13.5%) 28 (27.7%) 19 (25.0%)

Emotional wellbeing

Table 3.3 shows the responses when participants were asked about their feelings. At wave 1, nearly two-thirds admitted to being sometimes or often feeling worried and anxious. However over half had felt angry, down and lonely. By waves 2 and 3, these proportions had reduced but still just around half reported feeling worried or anxious. The other feelings had also reduced but over a third still felt angry, sad and lonely.

Table 3.3 The number and percentage of people ratings their feelings at wave 1 (n=127); wave 2 (n=101) and wave 3 (n=80)

Feelings	Never/hardly ever	Sometimes	Often/Always	Missing
In the last four weeks, how often did you Feel worried or anxious?	44 (35.2%) 49 (48.0%) 40 (52.6%)	58 (46.4%) 36 (35.3%) 28 (36.8%)	23 (18.4%) 17 (16.7%) 8 (10.5%)	2 (1.6%) 1 (1.0%) 4 (5.0%)
In the last four weeks, how often did you Feel angry or frustrated?	49 (39.2%) 62(60.2%) 48 (62.3%)	58 (46.4%) 35 (34.0%) 26 (33.8%)	18 (14.4%) 6 (5.8%) 3 (3.9%)	2 (1.6%) 0 3 (3.8%)
In the last four weeks, how often did you Feel sad or down?	54 (43.2%) 56 (55.4%) 50 (64.9%)	53 (42.4%) 33 (32.7%) 21 (27.3%)	18 (14.4%) 12 (11.9%) 6 (7.8%)	2 (1.6%) 2 (2.0%) 3 (3.8%)
In the last four weeks, how often did you Feel lonely with no-one to talk to?	54 (43.5%) 51 (50.0%) 51 (68.0%)	56 (45.2%) 37 (36.3%) 19 (25.3%)	14 (11.3%) 14 (13.7%) 5 (6.7%)	3 (2.4%) 1 (1.0%) 5 (6.3%)

Contact with friends and family

Table 3.4 summarises the percentage of persons rating their contacts with family and friend in each of the three waves. Most felt they had been able to stay in contact albeit through telephone and video calls. Fewer reported having no contact or occasional contact in Waves 2 and 3 as restrictions were lifted.

Table 3.4 The percentage of people rating their contact with family and friends

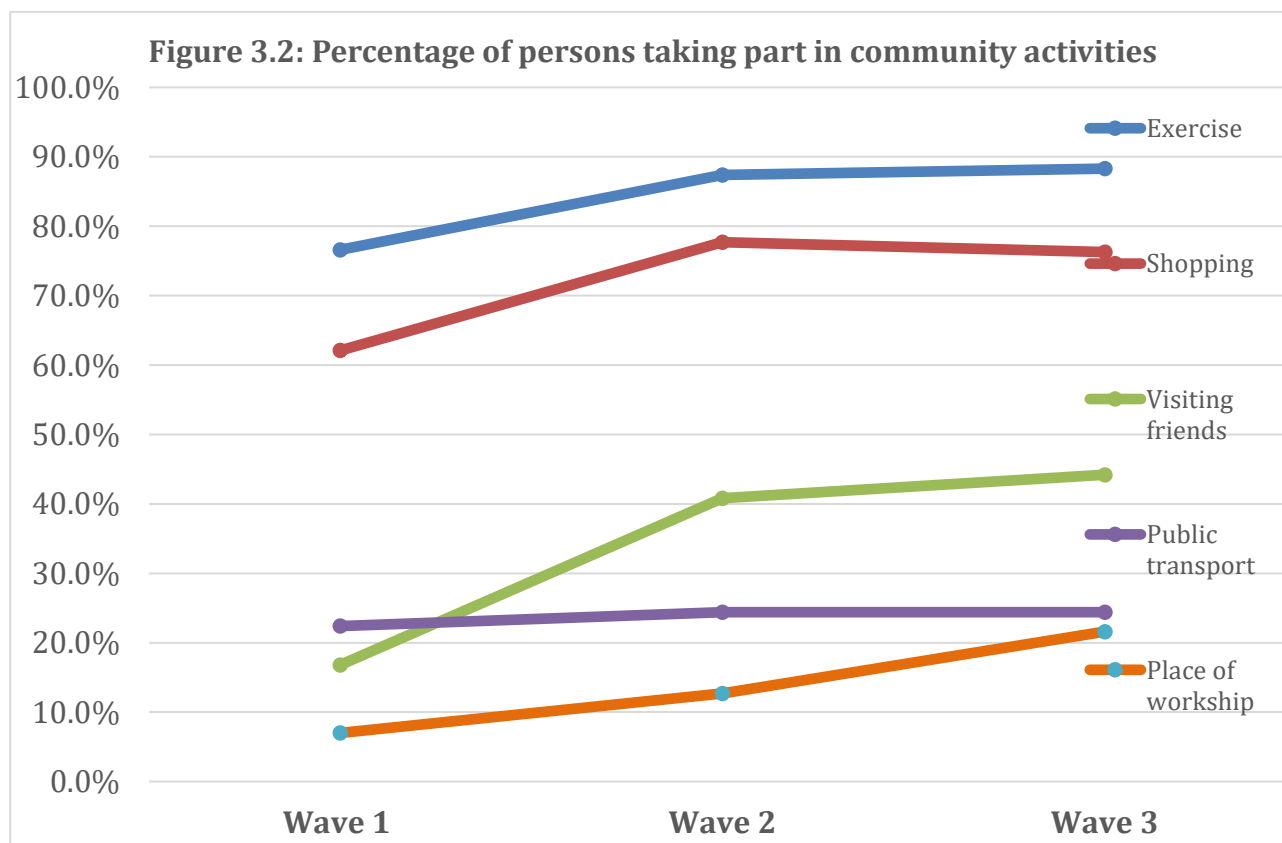
Contact	Wave 1	Wave 2	Wave 3
Yes, I stay in touch with family and friends as much as I want	70.4%	75.7%	80.4%
I'm not in touch with family and friends sometimes	17.6%	15.5%	9.1%
No, I'm not in touch with family and friends as much as I want	12.0%	8.7%	6.5%

However when asked what would make their life better right now, having contact with family and friends was frequently mentioned, as one person responded: *“Go back to work, get back to see friends and mates; going places with my mates, get out of the house to the bar and play pool.”*

Persons living in some form of supported accommodation (group homes, residential facilities) faced additional restrictions. At the start of 2021, 24.6% of residents reported that all visits were still stopped with 47.3% having to meet visitors outside although 29% had no restrictions. By mid 2021, 81% reported no restrictions on visiting although 20% still had no visitors or had to meet outside.

Community activities

Participants were asked if that had taken part in certain activities in the past week. Figure 3.2 shows the percentages who had done so and the changes over the three waves.



The most popular activities were taking exercise outdoors, such as walking, followed by shopping for food or medicines. Being able to visit friends in their homes did not happen much at Wave 1 but had increased by waves 2 and 3 although fewer than 50% of persons did so. The use of public transport remained steady and at a low level which may also reflect its availability in more rural areas. Attendance at a place of worship had increased over the three waves which may reflect the gradual easing of restrictions on indoor gatherings.

Access to services

People with learning disabilities are eligible for an annual health check at their GP practice. At Wave 1 at the end of 2020, 30% of those who usually get an annual health check had received one (with 27% done in person) but two-thirds had not had theirs. At wave 2, 17% had received a health check (11% done in person) and at Wave 3, 24.5% (15% in person). Thus upwards of three-quarters of people had not had a health check in over 18 months.

Table 3.5 shows the impact the closure of community health and social services in 2020 had on people with learning disabilities who had regular contact with the services listed prior to the lock-down (the numbers are shown in brackets). For nearly all services, people reported reductions or a lack of service. Home support services (for persons living independently) and community nursing were the ones most likely to be maintained or to increase their contact whereas work placements and respite breaks were the most affected.

Table 3.5 The percentage of persons reporting their contact with services after lock-down.

Service	Seen more than	Same as before	Less than before	Not seen at all
Social worker (n=55)		12.7%	30.9%	50.9%
GP (n=47)		11.6%	46.5%	41.9%
Psychiatrist/Psychologist (n=23)		21.7%	39.1%	39.1%
Community nurse (n=11)	8.7%	36.4%	36.4%	18.2%
Day services (n=43)			62.8%	34.9%
FE College (n=16)			43.8%	50.0%
Work/work experience (n=21)		4.8%	33.3%	61.9%
Respite breaks (18)		5.6%	33.3%	61.1%
Home support worker/personal assistant (n=25)	16.0%	40.0%	24.0%	20.0%

One year later, the services listed appear not to have resumed to pre-lock down levels of support: overall 13.0% reported in wave 3 that they were getting no support and a further 21.1% less support than before.

Impact on family carers

In all 45 family carers completed the online questionnaire at wave 1. Although the questions mostly focussed on their relative, the carers were asked if their health been

affected by their caring role in the past four weeks. Table 3.6 summarises the percentage of carers (n=45) who reported the feelings listed.

Table 3.6: The percentage of family carers reporting the feelings listed.

Feeling ...	%
Tired	68.9%
Disturbed sleep	60.0%
Stressed	57.8%
Short tempered/irritable	35.6%
Depressed	33.3%
Physical strain	22.2%

One mother commented: *“exhausted, emotional, worried about contracting Covid and how my sons will be cared for. Also worried about them contracting Covid”*.

Another wrote about the support she needed: *“Family Carers like myself feel abandoned, neither us nor the people we care for seem to matter, we feel forgotten about, look how far down the list we are to receive the vaccine. More flexibility with direct payments would enable us to choose who we pay to help support us right now”*.

Future reports

Further reports from the study are in the course of preparation that combine the responses from the four countries. They will provide further analyses to identify differences in the experiences of people with learning disabilities.

For example, those living with family carers or in their own homes had somewhat different experiences compared to those in some form of supported accommodation.

- People living with family were least likely to have been in contact with a community nurse in the last 4 weeks (including meeting a nurse in person) and also least likely to have seen a psychiatrist/clinical psychologist/counsellor in person in the last 4 weeks.
- People living with family were least likely to get any services, whereas people living alone or with a partner most likely to say they get less service support now compared to before the pandemic.
- People living with other people with learning disabilities least likely to see much of their neighbours since the start of coronavirus
- People living alone/with partner most likely to say they have felt lonely with no-one to talk to in the last 4 weeks

Reports will continue to be added to the Project website:

<https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/>

Section 2: The experiences of people with learning disabilities in Northern Ireland in their own words

A strength of this study was the interviews undertaken with people with learning disabilities so that they could recount at first-hand their experiences of Covid-19. In particular they were asked these questions in one or more waves of the study: *“What are your biggest worries about the coronavirus situation? Has anything good happened in your life because of the coronavirus situation? What would make your life better right now?”* Are there things you haven't been able to do because of coronavirus? What are you looking forward to doing this Summer when we can do more again?

In addition, the partner organisations collected similar account from their service-users.

This section brings together the main themes commonly found in their responses with illustrative quotes included.

Worries about Covid-19

Respondents had many worries about Covid and how it had affected their lives. The following themes were most common across all respondents.

Missing family and families

Being at home alone and not seeing friends and families. Not going out to the day centre.

Hope it ends soon and I can get a holiday and see my boyfriend.

I'm missing all my friends in college and my family. I don't get to see my family.

Not going home to see my family. It was hard not to cry when I could not go at Christmas.

Activities have stopped.

Being locked indoors - missed going out with friends, fishing, snooker, play pool, bookies.

I try not to think about missing gym, swimming, rugby, going to grandparents and friends and my Gateway Club.

Not being able to go to volunteer work, not seeing friends, going shopping; not having a night out with music and sing-song

Becoming ill

I'm petrified of it - I worry 24/7 because of my health problems

Worried about someone in my house catching the virus or being in close contact with someone.

Infecting other people because I work with customers in the supermarket;

Restrictions

Not going out of the house; worried about getting the virus; can't see people or go to their house; all closed down - no work placements.

Having to queue into shops; wearing masks - warm and can't breathe;

It's ruined my life; can't go bowling and go out with my care workers on outings. Have to stay at home. Can't go to people's houses.

Losing employment

I'm worried that I don't want to ever get the virus, worried about my job, my hours have been cut from 20 to 10.5 hours.

I might lose my job because of recession.

My worry is that I will not be able to have my operation, and I want to get a job, but I need this operation first.

Coping with Covid

Positive Futures asked their service users how the service had helped them cope. This is what they were told.

Information

“There were pictures that explained to wash your hands and wear a mask. The pictures helped yeah. We knew how to be safe outside by wearing a mask and using hand sanitizer. There was enough information.”

We were all in a difficult situation where rules kept changing – staff kept me updated but sometimes staff were confused themselves about rules and restrictions – but they did remarkably well in very difficult circumstances, they couldn't have done anymore.”

Keeping safe

Participants discussed how safe they felt during the pandemic and what concerns they had:

“I was concerned about going out while waiting for the vaccine. Staff reassured me by reminding me washing my hands and keeping distance was the best I could do.”

Participants shared some of the challenges with the safety measures:

We did two hourly cleans with staff and I kept thinking do they really need to do that. Staff helped me to understand why we need masks but once we are all vaccinated surely we will not need all the restrictions if we have distance and good ventilation.”

Vaccination

Participants discussed how much information Positive Futures shared with them about the vaccine and how they were supported to understand the vaccine and their right to consent:

“Positive Futures gave me an easy read document about the covid vaccine and they found out when I was getting it.”

“I realised if I did not get it I would have been more at risk due to some of my underlying conditions.”

“I knew I had a choice to not get the vaccine but I went and got it.”

“I got it in my left arm, it's getting better. I absolutely wanted to get it, it will keep me safe. I got a badge. I got my second one this morning it was much better than the first. The staff went with me. Everyone went together. I want a vaccine because of the virus. I completed a

consent form. They sat down with me and made sure I could read the words and I signed my name”

Quality of Life

Participants discussed how Covid-19 affected their quality of life and how they had been supported to adapt to new daily routines:

“What was life like during Covid? it was grand. I love cleaning the door handles, sweeping and dusting. I enjoyed the extra cleaning. Living with other people was ok, we went for long walks and picnics. I did arts and crafts, bingo, painting, gardening. Pamper nights – relaxing in a bath, reading books, having a chat, videos calls with family – I learned this during Covid”

“We went for walks, picnics, did basketball hoops, I couldn’t meet X, but learnt how to use Zoom and Teams to see her on the computer”

“My life completely changed, I used to go out at the weekends with friends and my boyfriend. Covid came and I couldn’t go anywhere but it kind of gave me time to focus on myself, things like walking/exercising more which improved my health and fitness. I continued to work through Covid but I was always worried I was going to lose my job- it kept me going.

“I missed going to coffee shops, swimming pool, shops. It was a bit of a mad house here at the start. I could not see my niece. I live with three other people which is grand but it’s hard to get alone time when everyone is here.

Participants shared what new activities they had taken up during the pandemic:

“I started teaching sign language at a university online during Covid – I’m hoping to meet my students in person soon.”

“I started to grow potatoes and carrots, baking, zoom calls – I kept myself busy at home – staff supported me with these things.”

“I am going to keep the new routine because it is a lot better, I’m less stressed. Things were generally less stressful during Covid but the only hinderance was not getting out as much.”

“I did a 6-week yoga course online. I did my raised bed and planted vegetables. We did teams meetings, quizzes, and advisory meetings with Positive Futures. I used Zoom a lot more to keep in touch with family.”

“My cooking skills have improved, my independent living skills have improved.”

“Staff helped me to adapt my whole routine and the changes have made me feel less stressed – so much so, I am not going back to my old routine.”

Did good things come from Covid?

In the surveys, respondents were also asked if good things had come out of Covid. Under half the respondents could not think of anything good that came from it but others named a range of ways they had benefited. This included:

Being closer to family and making new friends

I have a good support network - brought me closer to my family. Spending more time with my nieces and nephews.

I am enjoying the online zoom meetings and meeting new people. We had a school reunion.

Taking more exercise and being healthier

I have lost five stone doing online exercise classes with my mum.

More time to cycle - 2,000 miles since March

Don't do drugs anymore (pre-Covid).

Spending more time at home relaxing

I get to watch loads of films.

Spend more time with rabbits; read more; relax more; more calm in myself; not so anxious when with family.

I get to have more sleep in the mornings.

Time for hobbies

More baking at home; more gardening and planting flowers; joined Zoom training courses.

Watching more Ulster Rugby on laptop.

I bought new items for the house- getting it decorate.

Awareness of disability

One person spoke about how society might have a greater appreciation of what it means to be disabled.

People are getting a flavour of what life can be like for people with disability - they know what it is to have a lack of opportunity.

What would make life better right now?

Most respondents were able to think of one or more things that would make their life better.

Covid goes away and life goes back to normal

Getting rid of this darn virus. Not having to wear a mask when the virus is over.

I wish everybody would be able to travel. I'm sick being stuck in the house.

Meeting friends and family

If it would be over so I can see my friends and family. I don't like sitting about - I like to get out and do stuff. I haven't seen my brother since the virus. I haven't seen my foster family since the virus started.

Going out more, spending money, having a normal life again, seeing friends and boyfriend, being back to voluntary work.

Holiday

I'd travel around Ireland and overseas - been to New York. Stayed with my friend in Galway and would go again.

To go on holiday to Portugal, to swim, to see the sun, feel happy and warm!

Resuming activities

Everything back to normal, doing educational courses, getting back to Special Olympics and playing basketball.

Hopefully get back to normal - see friends, go shopping; go away to a hotel for the night. Want to learn to drive - I have applied for provisional licence.

Open all the shops. I want the bookies to open.

Getting back to work

Get back to my job working again - meet all my friends, go for drink.

More days working in Costa coffee shop. A couple of days a week would be better.

What were people looking forward to in the summer of 2021?

In Wave 3 in mid-2021, people were asked what they were most looking forward to doing that summer. Here are some of their responses.

"Going to the cinema with my dad, see my friends, visit my sister in Canada, enjoy holidays again"

"I'm looking forward to get back into work - I haven't been since March 2020; hopefully back into social groups; it's great to see events coming back - I like festivals and Christmas markets"

"I'll do some creative writing at home after taking online course through Zoom."

"Going to more political meetings"

"My marriage hopefully soon and I want to invite my family and his family over "

"Would love to do anything to get back to normal"

"I don't even want to hope"

Conclusions

People with learning disabilities endured the same Covid restrictions and deprivations as did many other citizens in Northern Ireland. They seemed to willingly comply despite the personal cost to them in not being able to visit their family and friends and to take part in the activities that formed part of their weekly routine. They also discovered new pursuits and ways of keeping in touch.

Their reflections on the Covid experience has brought out the things that are most important to people with learning disabilities and which professionals and service providers may easily overlook. Perhaps it is a salutary remainder of what needs to be taken forward into a post-Covid era so that indeed, we do build back better for their sake.