

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

Appendix 1: Coronavirus and People with Learning Disabilities Study in the UK.

Introduction

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Each nation had a team of researchers and partners involved in learning disability service provision. In Northern Ireland the research was led by Prof Laurence Taggart (Ulster) with Dr Peter Mulhall as full-time Research Fellow and Prof Roy McConkey as part-time Research Associate. The partner organisations were represented by Janet Schofield, Compass Advocacy Network (CAN); Brenda Aaroy (Families Involved in Northern Ireland (FINI), Mary-Anne Webb, MencapNI and Agnes Lunny, Positive Futures. They received a small financial recompense for their engagement in the study.

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The full set of research reports is available here:

<https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/results/wave3results>

The views expressed in these reports are those of the author(s) and not necessarily those of DHSC, NIHR, UKRI or MRC.

Background

There are approximately 1.5 million people with learning (intellectual) disabilities across the UK¹. Recent data indicate that people with learning disabilities are more likely to contract Covid-19, have a more severe case of Covid-19, and are three to six times more likely than people without learning disabilities to die from Covid-19^{2 3}.

People with learning disabilities are a very diverse group; while some people need 24-hour support others have limited or no social care support. Inequalities in health, wellbeing, social isolation, employment and poverty that existed before Covid-19, along with separation from family and friends and changes to routines, may have been exacerbated during the Covid-19 pandemic. User-led organisations, families and social care support providers have reported multiple challenges associated with social restrictions, maintaining infection control, and the provision of social care support to people and families. There have also been geographical variations in social and health care services' responses to Covid-19; in terms of both how and whether people receive support. These issues are described further in the first two brief reports from the project⁴ and are summarised in Table 3 below.

Current large-scale surveys, with their general population remit, are using methods (e.g., online surveys) likely to exclude most people with learning disabilities. Even when these surveys are nationally representative, they will not include sufficient numbers of people with learning disabilities to allow for meaningful analysis across different parts of the UK. They also do not have the flexibility to ask questions of specific relevance to people with learning disabilities. These larger surveys are typically being carried out without the specific resources and expertise that would enable the direct interview methods, with adapted questions and trained interviewers, needed for people with learning disabilities to participate.

¹ Mencap. (2021). How common is learning disability? Available at: <https://www.mencap.org.uk/learningdisability-explained/research-and-statistics/how-common-learning-disability> (Accessed on 9th March 2021).

² Henderson, A., Fleming, M., Cooper, S. A., Pell, J., Melville, C., MacKay, D., ... & Kinnear, D. (2021). COVID-19 infection and outcomes in a population-based cohort of 17,173 adults with intellectual disabilities compared with the general population. medRxiv.

³ Heslop, P., Byrne, V., Calkin, R., Huxor, A., Sadoo, A., & Sullivan, B. (2021). Deaths of people with intellectual disabilities: Analysis of deaths in England from COVID-19 and other causes. *Journal of Applied Research in Intellectual Disabilities*, 34(6), 1630-1640.

⁴https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/resultsoctober20/coronavirus_and_people_with_learning_disabilities_-_easy_read_v2.pdf
https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/resultsoctober20/covid19_key_issues_brief_report_v2_12.11.20.pdf
https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/resultsjanuary21/coronavirus_and_people_with_learning_disabilities_emerging_issues_report_easy_read_v2.pdf
https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/resultsjanuary21/covid19_key_issues_brief_report_25.2.21.pdf (all accessed 19 March 2021)

The project reported here uses these direct interview methods and is designed to systematically and responsively track the experiences of adults with learning disabilities through the Covid-19 pandemic over time across the UK, and investigate swiftly actionable factors associated with better outcomes.

This project is designed to have direct input from, and relevance to, people with learning disabilities and families, policy-makers, service commissioners, and providers of services across the UK throughout the 12-month project.

There are three 'Waves' of data collection to capture differences and changes over time during the Covid-19 pandemic from the same cohorts of people.

There were two cohorts of participants: Cohort 1 are adults with mild/moderate learning disabilities who took part in an interview with a researcher, and Cohort 2 were family carers and support staff of adults with learning disabilities who could not take part in an interview themselves, including people with more severe, profound and multiple learning disabilities (PMLD).

The research focused on three key questions:

1. What are the wellbeing, health, and social effects of the Covid-19 pandemic, including social restrictions and changes to how people are supported, on the lives of adults with learning disabilities across the UK over time?
2. What actionable factors are associated with better outcomes for different groups of people with learning disabilities?
3. What urgent issues concerning people with learning disabilities are emerging over time?

Study Methods

How did we find people?

Recruitment of people into the study was facilitated through multiple methods, including through collaborating organisations, social media, and wider networks of learning disability and family organisations across England, Northern Ireland, Scotland and Wales. Potential participants could express interest in the study via telephone, email, social media, or clicking a link to the survey (for family carers and support staff only) on the project website. People in both cohorts self-selected to take part.

Who took part?

Initially 1,000 people with learning disabilities (Cohort 1) across the UK (400 in England and 200 in other nations) were to be recruited along with 500 family carers or paid support staff of people with learning disabilities who could not take part in an interview themselves (Cohort 2). This was broken down by country, with a target of interviewing 400 people with learning disabilities in England and 200 each in Northern Ireland, Scotland, and Wales. For the surveys with family carers or paid support staff, we aimed to receive responses from 200 people in England and 100 each in Northern Ireland, Scotland, and Wales. However these targets were not met and Table 1 gives the numbers broken down by each nation.

The shortfall was proportionately greater in England with Northern Ireland and Wales having the highest proportions per hundred thousand of the general population.

Table 1: The number of participants by each nation recruited to the project at Wave 1.

Nation	Cohort 1 (People with LD)	Proportion per 100,000 pop.	Cohort 2 (Carers)	Proportion per 100,000 pop.
England	181	3.21	126	2.24
Wales	149	47.3	77	24.4
Scotland	159	29.1	113	20.7
N. Ireland	127	67.1	62	33.27
Total	616		175	

This makes the survey one of the largest internationally involving people with learning disabilities.

Selected demographic information is presented in Table 2 for both cohorts at Wave 1.

For Cohort 1, most of the participants were aged 16-44 years (68.2%), just over half were men (51.3%), the vast majority were white (94.7%), and 11% were people with Down syndrome. Substantial proportions of participants in Cohort 1 were living with their family (41.4%), living alone or with a partner (36.3%) or living with other people with intellectual disabilities in some form of supported housing or residential accommodation (22.3%).

For Cohort 2 most people with intellectual disabilities were aged 16-45 (80.8%), a majority were men (56.5%), and the vast majority were white (94.1%). Almost half were people with 'Profound and Multiple Learning (Intellectual) Disabilities' (44.0%) and 18.3% were people with Down syndrome. Most adults with intellectual disabilities in Cohort 2 were living with their family (63.6%), relatively few people were living alone or with a partner (10.7%), and a quarter of people were living with other people with intellectual disabilities in some form of supported housing or residential accommodation (25.7%).

Table 2: The characteristics of participants in the study

Demographic variables	Cohort 1 (interviews with adults with learning disabilities)	Cohort 2 (surveys with family carers and support workers)
Age		
16-44	n=416 (68.2%)	n=291 (80.8%)
45+	n=194 (31.2%)	n=69 (18.3%)
Gender		
Male	n=312 (51.3%)	n=204 (56.5%)
Female	n=296 (48.7%)	n=157 (43.5%)
Ethnicity		
White	White n=588 (94.7%)	White n=348 (94.1%)
All other groups	Other ethnic group n=33 (5.3%)	Other ethnic group n=22 (5.9%)

Person with Profound Multiple Learning Disabilities (PMLD) Yes Not sure/No	Data not collected	n=164 (44.0%) n=209 (56.0%)
Down syndrome Yes No	n=67 (11.0%) n=540 (89.0%)	n=68 (18.3%) n=304 (81.7%)
Living situation Living with family Living alone/with partner Living with other people with learning disabilities	n=247 (41.4%) n=217 (36.3%) n=133 (22.3%)	n=213 (63.6%) n=36 (10.7%) n=86 (25.7%)

Co-production

The project was co-produced between university researchers and advisory groups of people with learning disabilities and family carers of people with profound and multiple learning disabilities (PMLD). In each nation, an advisory group of service providers was also recruited. At the outset, consultations were held with these partners. The key issues they focused on are summarised in Table 3.

Table 3: Key issues identified by research partners

Changes in Support:
Reduction or removal of support has been and remains a major issue for people with learning disabilities and their families. Concerns were raised about the impact of the withdrawal or reduction of support and also about changes in assessment processes.
Health concerns:
Several issues of concern relating to health were raised: fear and anxiety about catching coronavirus, worries about the impact of the pandemic on the mental and physical health of people with learning disabilities and their families, changes in access to medical care, and concerns regarding medical decision-making around issues such as Do Not Attempt Cardiopulmonary Resuscitation Orders (DNACPRs).
Lack of access to family members in residential care/hospital:
A prominent issue among family carers is their lack of access to their relatives in residential care due to restrictions on visitors. Some family carers with a relative with profound and multiple learning disabilities had not had any face to face contact with their relative since before the pandemic.
Lack of information:
Another issue was a lack of clear guidance and accessible information on coronavirus and associated restrictions. Specifically, a need for clearer guidance on shielding, PPE and testing was identified.

Experience of using digital platforms:
Digital exclusion was a key issue among people with learning disabilities. People with learning disabilities may not have access to digital platforms, either due to lacking appropriate equipment (e.g. smartphone/tablet, the internet), and/or because they lack the skills or confidence to navigate new digital platforms. This affects individuals' access to current support and social activities. Some older family carers who do not have access to this technology have also struggled to communicate with their relatives in care homes where restrictions prohibit visiting.
Impact on the carer:
The coronavirus pandemic has affected both the mental and physical wellbeing of family carers. Carers are taking on significantly greater caregiving duties, with usual services such as day centres, community teams and respite currently closed and other supports withdrawn.

Conclusions - The impact of restrictions

There is no doubt that the specific coronavirus restrictions have clearly affected the lives of people with learning disabilities and their families across the UK. Social distancing restrictions are a barrier to the usual communication method of many people with profound and multiple learning disabilities as they prohibit physical touch. Shielding has significantly increased social isolation for both people with learning disabilities and their families, many of whom have been shielding since the outbreak of the pandemic. People with learning disabilities and their families feel society has forgotten about them. The increased anxiety around all the changes, including changes in support and access to medical care, has left people with learning disabilities and family carers experiencing a loss of control in their lives.

How the interview schedule and surveys were developed

The interview schedule and survey were designed in consultation with the research partners; drawing also in the experiences and insights of the university team.

1. We asked people with learning disabilities and family carers from across the UK about the issues that were important to them in October 2020, before we started developing the Wave 1 interview and survey.
2. We asked advisory groups in each country to provide their feedback on the drafted interview and/or survey.
3. We consulted further with advisory groups from across the UK for the interview and survey before we started data collection.
4. We continue to routinely ask these advisory groups about urgent and emerging issues; this is particularly the case at the start of each Wave of survey development.

A structured interview schedule or self-completion questionnaire was developed with a number of choices listed from which the participants could select one or more depending on the topic. A few open questions were also included with responses being typed into the questionnaire.

Ethical considerations

Ethical approval was obtained from Manchester Metropolitan University. An accessible information sheet about the project was prepared and circulated to prospective participants. A copy is available at: https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/countries/englandcontact/england_study_information_sheet.pdf

An audio-recording was made of the participants consenting to take part in the study and these are held by Manchester Metropolitan University by code number only. For Cohort 2, answering the questions was taken to imply consent.

No names of participants are recorded on any data files.

As the access to participants was through non-statutory agencies, an ethics application to a Research Ethics Committee was not required.

How the information was collected

Cohort 1: Adults with learning disabilities

Participants in Cohort 1, were directly interviewed by a university employed researcher via Zoom, telephone, Microsoft Teams, WhatsApp video call, Messenger video call, and FaceTime. Interviews were undertaken using the preferred digital platform or on the telephone for each participant. Participants were also able to have a supporter of their choice (e.g., family member, support staff) present at the interview. In all cases, flexibility was paramount to ensure that people with learning disabilities were able to participate in their preferred way. Interviews took, on average, 45 minutes to complete, and were usually completed in one sitting. Short breaks were offered during interviews when needed.

Data were entered directly into Qualtrics™ software during the interviews by the University researcher. A very small number of participants chose to self-complete the questionnaire online.

Cohort 2: Family carers and paid support staff of adults with severe/profound learning disabilities

We also collected information about a cohort of adults with learning disabilities who were not able to take part in an interview with a researcher. In most instances, these individuals were likely to have severe/profound learning disabilities (although we do not have direct information about these individuals' level of learning disability). A group with high support needs who were unlikely to be represented in any large scale experience surveys. To gather data on this group, we surveyed their family carers or paid support staff using an online self-completion Qualtrics™ survey.

In Cohort 2, at the outset participants were the family carers and paid support staff of 378 adults with learning disabilities; 83% of whom were family carers of an adult with learning disabilities and 15% of participants were paid support staff of an adult with learning disabilities. The remaining 3% of participants were other people who knew the adult with learning disabilities very well (e.g., a friend).

Three waves of data collection

The study involved re-interviewing participants at two further time points as shown in Figure 2. As is the case with longitudinal studies, the number of participants decreased in later waves.

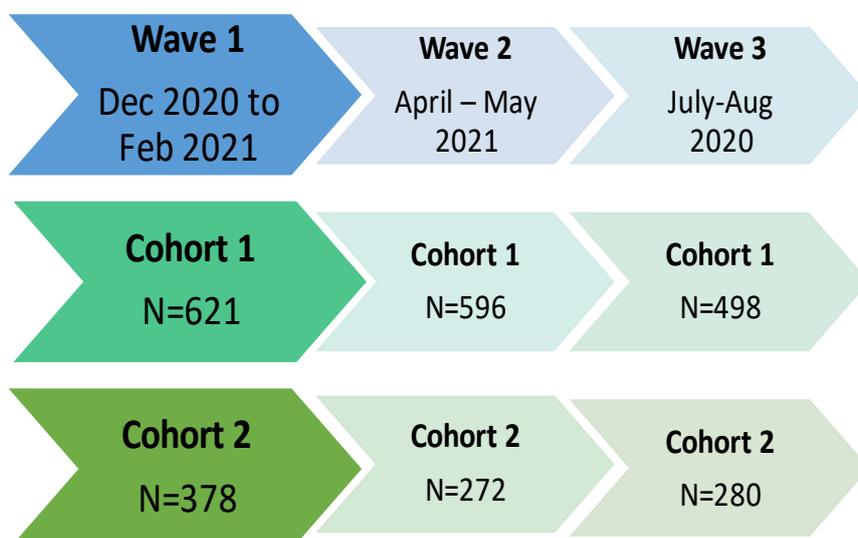


Figure 2: The number of participants in each wave of the study.

Bar a short period over Christmas 2020, lock-downs were in place in all four nations during January and February 2021. From April onwards these had begun to ease, albeit in different ways across the four nations.

How the information was analysed

Quantitative data

The analysis for Waves 1, 2 and Wave 3 that has been undertaken to date is largely descriptive, with percentage estimates relating to the responses for individual survey items. However future papers will contain deeper analyses of the data gathered.

Data from Cohort 1 and Cohort 2 were analysed separately and, where appropriate, descriptive comparisons have been made between the two cohorts.

Statistically significant differences across subgroups (for example, based on age above and below 45, and whether the person with learning disabilities lived with family or not) on percentage endorsement of items were first derived from Chi Square analysis; with resultant odds ratios reported as effect size estimates in subsequent regression analyses. The reports from the project only include the findings from these comparisons where there were statistically significant differences.

It was also the case that some survey items related to sub-groups of people. If so, we report the number who completed the question alongside the percentage estimates. All analyses were conducted in SPSS v.27. To aid interpretability, percentage estimates were rounded off to the nearest whole number. The sole exception to this was when percentage estimates were between (and exclusive of) 0% and 0.5%, in which case we used <1% to signify such instances.

Qualitative data

There were a series of open-ended questions asked of both cohorts. For Cohort 1, researchers conducting the interviews typed the responses into text boxes on Qualtrics™. For Cohort 2, participants typed their responses into the text boxes in the online survey.

Selected responses from open-ended questions for both cohorts in Wave 1 have been included in Boxes throughout the project reports to provide additional context to the descriptive data and to give more detail about the Covid-19-related experiences of participants in both cohorts. Included responses have been chosen to illustrate the overall responses made to the open-ended questions. An analysis of the themes within the qualitative data is given in Appendix 3 of the present report.

Comparisons with other national surveys

Where comparable data were available from other national surveys, they are included in the project reports as a comparison with our study data. Where appropriate, throughout the report, we state the study/survey from which the data originated, describe the findings, and compare them to ours.

Limitations of the study

Despite the uniqueness and considerable strengths of the study, there are some limitations that need to be borne in mind.

- Recruitment to the study was limited to persons with learning disabilities known to services provided mainly by the non-statutory, voluntary sector. The time-scale for the study set mainly by the funder could not accommodate the research governance requirements of NHS trusts and social services. However many of the respondents to the survey also used statutory health and social care services.
- The people approached to take part in the study were selected by the partner organisations and in turn, individuals chose to join the study. This may have resulted in biases within the sample that are not easily identified as comparisons with population data was often not available.
- Given the differences in the numbers of people in each of the four countries, Northern Ireland and Wales are over-represented with England under-represented.
- People with learning disabilities who were not in receipt of services did not take part in the study.
- The family carers who were recruited to the project had relatives who were aged 16 and over. The study did not include carers of younger persons. Moreover the focus with carers was mainly on the impact of Covid on the person with learning disabilities.
- The experiences of people with more severe and profound disabilities were not obtained directly but rather by proxy informants such as family carers and paid carers.

- People living in residential and nursing homes or in specialist hospital settings were not included in the study.

Reports of findings

To date, the findings in Waves 1 and 3 have been collated in two full reports, with briefing papers written on specific topics from Wave 2 findings as well as those from the other two waves. Easy-read versions of the briefing have also been prepared. These are all available for downloading from the project web-site.

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

The project is ongoing and will end in December 2021. Further data analysis will take place and other articles and papers will be prepared.

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