



Coronavirus and people with learning disabilities study -

The impact of the COVID-19 pandemic on people with learning disabilities and factors associated with better outcomes

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A UK wide study is looking at the impact of the Covid-19 pandemic on the lives of people with a learning disability. There are many surveys taking place across the country on this issue. However, these may not be accessible to people with learning disabilities and even if they are, no record is made whether participants have a learning disability or not. This study therefore ensures that the experiences of people with learning disabilities, and those who support them, are recorded, and understood. The study is funded by UK Research and Innovation. Further information about the study is available on the website www.covid19learningdisabilities.co.uk

The study is being conducted across the four countries of the UK. In Wales, it is led by Professor Stuart Todd and Dr Edward Oloidi from the University of South Wales and Dr Steven Beyer from Cardiff University. They are being supported by All Wales Forum of Parents and Carers of People with a Learning Disability, All Wales People First and Learning Disability Wales.

The research is carried out with 2 groups of participants or cohorts. The first group are people with a learning disability who are taking part in interviews with

researchers. The second group are family carers or paid support staff who complete an online survey on behalf of a person with a more severe learning disability.

Participants are interviewed or asked to complete a survey during each of the three waves/ phases of the study. This enables any changes during the yearlong study collection to be captured.

First Wave / Phase of the Study – December 2020 to February 2021

The data for the study covers many areas of peoples lives and some findings from the first wave / phase of data collection are summarised below. The findings of this phase are broken down into the two cohorts / groups as it is important to recognise the different experience of people with a more severe learning disability.

Cohort / Group 1: Face to face interviews with people with a learning disability

149 people with a learning disability were interviewed. 51% of those interviewed were women. Just over 50% were under 35years old, 35% between 35 and 54 years of age, and 11.5% were 55 years of age or older. 97% reported that they were white. Almost two thirds reported that they lived in a city or town, and almost the same number reported that were single. 7 people lived with a partner, 31 lived alone (with or without support) and 69 lived with their families. 6 were in Shared Lives and 36 lived with other people with a learning disability (with or without support)

Living with coronavirus

About 4 in 10 people said they did not find it easy to find good information about coronavirus but most were sure that they knew the rules concerning social distancing (85%). The most likely sources for getting information were family (52%), support staff (36%), social media (36%) and TV (81%).

Most people had not been tested for the virus (69%). Of the 45 people who said they had been tested, 6 said that they had received a positive result. Another 12 people said they thought that they had had the virus but had not been tested. From those with a positive result and those that thought they had had the virus (n=18), 5 had been hospitalised because of their symptoms.

About 1 in 3 people said they worried a lot about contracting the virus (30%). While 55% said they were concerned that family or friends might contract it, 1 in 3 said they worried about passing on the infection to others. 26 people said that they had a relative or a friend die from Covid19 (17%). Just under a third of people (30%) reported that they worried a lot about leaving home.

Health

Health was an important focus for the study. 62% of people reported that at the time of interview their health was good while 33% said it was ok. 45% of people interviewed said that they had an underlying health condition that made them concerned about catching coronavirus and 40% said that they had shielded. This reminds us that people with a learning disability have a unique health profile and even before the pandemic had a high level of healthcare need.

Some people reported that their health was worse during lockdown. 57% of people said they had seen their GP less often than before and 30% said that a planned medical test had been cancelled. To promote early detection and treatment of health problems, people with learning disabilities are entitled to an annual health check. Since March 2020, 39 people interviewed who normally had an annual health check (n=107) said that they had either received an annual health check or had one booked (36%). Of the annual health checks that had been completed, half were done by telephone or video. More people (62;58%) who normally had an annual health check reported that they had not had one since March 2020.

Well-being and Social

Although 42% said that they hardly ever felt lonely during the time data were collected, 1 in 4 (25%) said that they often had. A similar number said they felt sad and tearful most or all of the time. 1 in 3 people also reported feeling worried or anxious often in the 4 weeks before the interview.

About 2 in 3 people reported that they had been able to stay in touch with family and friends as much as they wanted but almost 1 in 3 said that this was not the case. Nearly everyone had access to the internet (97%) and most used Zoom or other online platforms to keep in touch with family and friends. People with learning disabilities have been reported to have fewer opportunities for developing and maintaining social relationships than other people. This has probably been exaggerated further during the pandemic. The potential of computer-based platforms to facilitate community participation and relationship building in the future is worth addressing.

Access to Support

Of the people who reported on seeing a social worker, 28 (52%~) said they no longer had since March 2020, and 21 (39%) less often than previously. Many people with a learning disability and their families rely on support from day services or support workers. Of the people who had used a day service before March 2020, 71% said they had not done so since. 1 in 3 people who went out with personal assistants or support workers before lockdown did not do so during lockdown and around half said that they had not gone out with them as much as before. This meant that people with a learning disability were more likely to be dependent on their family and others that they lived with for support and advice. However, there was some sense that there was variation across the country concerning access to and the availability of support.

Employment

43 people interviewed were in employment in March 2020. Most (51%) said that they still were. Only 5 (12%) said they no longer had a job. The remainder were either furloughed or believed their job was being kept open for them to return to in the future. 79 people said they had a voluntary role in March 2020, most of whom reported they were either still doing this or would return to it after lockdown while 15 (19%) said they no longer had this voluntary role. About a third of people said they worried a lot about what the pandemic would mean for their future employment prospects. Only 6% of adults of adults with a learning disability are in employment and there is concern those opportunities may be further diminished in the future

Cohort / Group 2

Cohort/ group 2 data was provided by paid support staff or family carers completing an online survey on behalf of a person with learning disabilities. This meant that the study would also have data about what was happening to people with more severe learning disabilities. 71 of the 77 people completing the survey were family carers and the rest were support staff.

41 of the people with a learning disability were men and 36 women. They were largely younger adults with over a half aged under 35years (60%). The remainder were more or less evenly divided between those between 35 and 54 years of age (21%) and those who were 55 years of age or older (19%). The vast majority were reported to be white (92%). About 1 in 4 people (27%) were people that respondents said that the term 'profound and multiple learning disabilities (PMLD) would be appropriate. 17% were reported to be people with Down Syndrome. Half of the people with learning disabilities were living with a family member and 37% lived in a supported living or care home setting. Just over 2 thirds of people reported that they lived in a city or town (69%).

Living with coronavirus

About 2 thirds of people with learning disabilities (64%) were reported to have a health condition that made the respondent worried about a potential coronavirus infection, and 35% were said to have shielded. Most people with learning disabilities had not been tested for the virus (69%). Of the 22 people who had been tested, 4 had received a positive result. 37 respondents knew that support staff had been tested and had been told the result of that test. In 51% of cases at least 1 member of support staff had tested positive. Family carers reported that at least 1 relative had tested positive in 13 cases. Where people were living with other people with learning disabilities, and the respondent had knowledge of their coronavirus status, just over a quarter were aware of at least 1 other person with a learning disability they were living with who had tested positive for the virus. About 1 in 10 people reported that the person had a friend or family relative die from coronavirus (8%).

Health

45 out of 75 people said that the health of the person they cared for was good (60%) or OK (27%). Although the health of most people was reported to be the same since March 2020 (26%) were said to now be in poorer health. Around 3 quarters of the people with learning disabilities regularly used medicines. Prior to March 2020, 33 people (46%) said the person they cared for, regularly saw a GP and 2 thirds of those (61%) said they had not seen a GP since then and 6 (18%) said they were seen less often than before. A third of people reported that they usually saw a learning disability nurse regularly prior to March 2020. Of these, two thirds (67%) said they had not been seen at all since March 2020 and a further 25% said they were seen less often than usual. 20 people (28%) said a planned medical test had been cancelled and 28 (40%) that a planned medical appointment had been cancelled. 82% of people usually had an annual health check but only 21% of these individuals had received an annual health check since March 2020 or had one booked.

The majority of the annual health checks completed were done by video (83%). As for cohort/ phase 1, people here had a high level of healthcare need but found that access to health care was severely restricted during the months of data collection.

Well-being and Social

65% were reported to be more worried or anxious; 62% more sad or down and 65% angrier or more frustrated since March 2020. Most people reported having experienced restrictions in visits or having visitors (94%), and about 1 in 4 people with learning disabilities had not been visited by others from outside of their home or had made visits to the homes of others at all since March 2020. However, people with a learning disability found other ways of interacting with family or friends with 15% using via zoom or facetime before the lockdown increasing to 69% after the lockdown. Similarly, 34% kept in touch via talking on the telephone before the lockdown increasing to 56% after.

Carers

Carers were also asked questions about the impact their caring role had had on them in the 4 weeks prior to completing the survey. Only 8% said their caring role had had no negative impact on them. The most commonly reported impacts were general stress (68%), sleep disruption (64%), feeling tired (60%), depressed (47%) and physical strain (21%). 13% reported having had to contact a GP for themselves in the previous 4 weeks prior to completing the survey.

Access to Support

42% of people said that the person with a learning disability regularly saw a social worker prior to March 2020. Almost two thirds of these (64%) reported that they had not seen one at all since then. Just over a half of people were reported to have attended a day service prior to March 2020 but 70% had not attended

since then. 78% were reported to have taken part in community activities prior to lockdown but 83% of these had not taken place during lockdown. Around 1 in 3 people were reported to have used respite care prior to March 2020, and 70% now had no access to such services. Once again, a group of people that confront challenges in social and community participation prior to the pandemic were now more restricted.

Employment

3 quarters of those that were in employment or work experience prior to March 2020 had not been to their job or work experience since then.

Summary

People with learning disabilities already needed improved access to quality healthcare and effective support before March 2020. Opportunities to access both diminished during the pandemic and this had a significant impact on the lives of people with learning disability. Many have come closer to coronavirus than other people because of the nature of the support they receive. The anxieties people with learning disabilities have faced are significant. Reduced access to support services and higher levels of loneliness and isolation have compounded this. The response to the virus is changing in Wales. Vaccinations are being rolled out and there has been some easing of restrictions. How these impact on the lives of people with a learning disability and to what extent are they being offered and accepting the vaccine are questions that are currently being asked to our study participants in Wales.

Using the findings of the study

The team, behind the research are keen to share the findings of the study as widely as possible as and when the data becomes available. One of the ways we are doing this is to hold a series of online events Our first event on was held

on the 17th May 2021. People with a learning disability, family carers and service providers shared their experiences of the pandemic

Second Wave / Phase of the Study - March to May 2021

In Wave 3 of the study the number of people with a learning disability interviewed increased from 149 to 183. However the number of people completing an online survey on behalf of a person with a learning disability decreased from 77 to 51. Data from this wave of the study has been compiled into 4 thematic briefings and headlines from these are shared below.

Risks and Coronavirus

55% of people with a learning disability we spoke to in wave 1 reported that they had an underlying health condition that made them concerned about catching Covid 19. For people with severe and profound learning disabilities this increased to 64%.

In Wave 2 we learnt that 1 in 7 of people with a learning disability had been tested for covid 19 in the month before their interview. 10% of people had been confirmed as having covid 19. Paid support staff or family members were reported to use masks, gloves and aprons with 70% of people with a learning disability but only 40% people with a severe or profound learning disability. It is unclear while this difference has occurred. 7 out of 10 people with a learning disability researchers spoke to said that they were living in services which had imposed some limits on people visiting them. For people with a severe or profound learning disability, this increased to 8 out of 10 people. 1 in 10 people with a learning disability had self-isolated in the last month.

5% of people with a learning disability researchers spoke to said they were shielding. This increased to 25% of people with a severe or profound learning disability. This reflects the additional health challenges faced by this group of people. 20% people with a learning disability worried a lot about getting Covid

19 themselves while 40% of people with a learning disability worried about friends and family getting Covid 19.

About 10% people with a learning disability told researchers that they were concerned about going out. However in the week before the interview, 70% people with a learning disability had left the house to exercise outdoors; 80% had gone shopping for food or medicine; 50% had gone to get a takeaway and 30% had left the house to use a bus or train.

For people with a severe and profound learning disability, 60% of people had left the house in the week before the interview to go out in a car; 60% had gone to the park; 20% had gone shopping for food and medicine while 30% had left the house to exercise outdoors. 20% people with a learning disability told researchers that they did not have to wear a mask when out and this increased to 50% of people with a severe and profound learning disability.

Click on the hyperlink to open an easy read briefing <https://bit.ly/3xomoqp>

Vaccinations

In Wave / Part 2 of the study we learnt that 90% of people with a learning disability in Wales had received one dose of the vaccination while 30% had received both doses. 17% of people with a learning disability said they thought it was hard to get an appointment for the vaccination because their learning disability was not recorded in their notes. People with a learning disability said that having paid support staff or family carers with them when they received the vaccine helped them feel more relaxed. It also helped if the people giving them the vaccine took time to speak to them and explained what was going to happen. Some people with a learning disability were given the vaccination at home or sitting in a car outside a surgery. They reported that they found this less upsetting than going to a big vaccination centre.

64% of people with learning disabilities said they felt a bit unwell or sore after receiving the vaccination. Other symptoms included having a headache, sore arm, difficulty sleeping, upset stomach, feeling hot or cold or feeling sick.

Click on the hyperlink to open an easy read briefing <https://bit.ly/2X1ili2>

Digital Lives

Nearly everyone, 98% of people with learning disability told researchers they had the internet at home while 92% said they used the internet at home. However this does not necessarily mean that they used the internet independently or whenever they want to. 98% of people with a learning disability said that they had a phone they could use. All people with a severe or profound disability had the internet at home but only a third used it. Just under half of people with a severe or profound learning disability (41%) had a phone they could use with help.

88% of people with a learning disability used the internet every day. 72% made or were supported to make video calls with friends while just over a half (53%) used FaceBook. 17% of people with a learning disability played video games online while a 50% watched films and television online. 60% of people with a learning disability attended online groups and some 34% went shopping online. 84% of people with a severe or profound learning disability were offered online activities. 10% of people used to enjoy these activities but no longer did, while 42% had never enjoyed them. The same percentage (42%) had always enjoyed these activities.

Click on the hyperlink to open an easy read briefing <https://bit.ly/3yA9Aio>

Impact of Caring

66% of the 51 family carers and paid support staff, said that in the four weeks before they completed the survey, said that they had enjoyed good health. However 60% said that they had been feeling tired while the same percentage

felt stressed. 40% said that they had been feeling cross. These are some of the things that they told us might help them.

- “I’d be more relaxed if my son was given his second Covid 19 vaccination and I had a speedier response from the professionals when I contacted them about the issues that arose”
- “Clarity about how to stay safe as we move into a new stage. Many people are vaccinated but we still need to be careful”
- “Resume services so I can have a good night’s sleep and have some time to myself to go for a nice walk”
- If the care home was more flexible and did individual risk assessment, he may have been able to have some contact with us”

Click on the hyperlink to open an easy read briefing <https://bit.ly/3jxXhN9>

The final phase of data collection began in July.

This project was designed to have direct input from and relevance to policy-makers, service commissioners and providers, people with learning disabilities and families across the UK throughout the 12-month project. The team, behind the research are therefore keen to share the findings of the study as widely as possible as and when the data becomes available. A second event took place on 21st June 2021. As well as sharing what we have learnt from [the s12study](#), we discussed what it meant for service provision and the development of policy for people with learning disabilities in the future.

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All Wales Forum
Giving a national voice to empower parents
& carers of people with a learning disability



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