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The experiences of adults with learning disabilities during the COVID-19 pandemic

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Conflicts of interest: None

Abstract

Purpose

This paper presents data about the experiences of adults with learning disabilities during the COVID-19 pandemic across the UK.

Methodology

Interviews were conducted with 609 adults with learning disabilities. Family carers and support staff of another 351 adults with learning disabilities completed a proxy online survey. The data were collected between December 2020 and February 2021 and concerned both worries/negatives and anything positive that had happened because of the COVID-19 pandemic.

Findings

Social isolation was the most commonly reported worry/negative for adults with learning disabilities, with other frequently reported worries/negatives including: changes to/loss of routine; loss of support, clubs, or services; decreased health, wellbeing, or fitness; and, worries about themselves or other people getting COVID-19. A large proportion of participants indicated that nothing positive had happened because of COVID-19, but for participants who did report a positive, this most commonly included: digital inclusion; more time spent with important people; improved health; wellbeing, and fitness; and, a slower pace of life.

Implications

Future pandemic planning must ensure that adults with learning disabilities are supported to maintain social contact with the people who matter to them, and to support their health and wellbeing (including maintaining access to essential services and activities). Some adults with learning disabilities may benefit from additional support to improve their digital confidence and access. This may in turn enable them to maintain contact with family, friends, and support services/activities.

Originality

This is the largest study about the experiences of adults with learning disabilities during the COVID-19 pandemic in the UK. We primarily collected data directly from adults with learning disabilities, and worked with partner organisations of people with learning disabilities throughout the study.

Key words: learning disabilities, COVID-19, social isolation, digital inclusion, health, well-being

Introduction

This paper provides an overview of the experiences, worries/negatives, and positive things to happen to adults with learning disabilities across the UK during the COVID-19 pandemic between March 2020 and the data collection period (December 2020-February 2021).

Large-scale surveys about people's lives and experiences during the COVID-19 pandemic have tended to use methods (e.g., online surveys) that either exclude or do not identify people with learning disabilities (e.g., Understanding Society, 2021). Even nationally representative surveys are unlikely to have enough people with learning disabilities to enable meaningful analysis and may not ask questions of specific relevance to people with learning disabilities. Thus, there is a risk that the experiences of people with learning disabilities across the UK are not represented in discussions about the impact of the pandemic.

This *Coronavirus and people with learning disabilities study* (2021) sought to address these issues by collecting data directly from adults with learning disabilities using direct interview methods and focussing on key issues highlighted as important by partner organisations involving people with learning disabilities and family members.

Methodology

During the first wave of the *Coronavirus and people with learning disabilities study* (Flynn et al., 2021), we collected data across the UK directly through interviews with 621 adults with learning disabilities (Cohort 1). We also conducted an online survey of 378 family carers and support staff of adults with learning disabilities who could not take part in an interview with a researcher themselves (Cohort 2). In many instances, the individuals reported about in Cohort 2 were likely to have severe/profound learning disabilities (although we do not have direct information about these individuals' level of learning disability). Adults were defined as being aged 16 and over in England, Scotland, and Wales, and 18 and over in Northern Ireland.

The data were collected between December 2020 and February 2021. Full details of the survey methods and participants can be found in Flynn et al. (2021).

Dataset

The data presented in this paper focus on two open-ended questions from the Cohort 1 interviews (1. "What are your biggest worries about the coronavirus situation?" and 2. "Has anything good happened in your life because of the coronavirus situation?") and the Cohort 2 survey questions (1. "What has life been like for the person you care for/support during the pandemic?" and 2. "Has anything good happened in the life of the person you care for/support because of the coronavirus situation?").

In total, 609 adults with learning disabilities in Cohort 1 and 351 family carers or support staff of adults with learning disabilities in Cohort 2 completed one, or both, of these questions and were included in these analyses. For Cohort 1, interviewers captured verbal responses of participants. Thus they largely represent summary notes of what participants said in interviews. For Cohort 2, participants typed their responses directly into the online survey.

Content analysis was used to analyse the qualitative data from both cohorts, and anonymised data will be used in the results section. Some participants' responses to the questions contained more than one concept, so each new thought was coded separately.

To establish inter-rater reliability, the first author coded all data and ensured that there was a Kappa coefficient of at least 0.6 with second raters, for 20% of the data for both cohorts. Once this level of correspondence was established, and any disagreements were resolved with second raters, the first author adjusted the coding approach and continued to code the datasets.

Results

All codes for both cohorts are presented in Table 1. These are broken down into two categories: 'Worries/negatives' and 'Positives'. All data from all four of the questions were available for coding into all the codes within both categories. The numbers in each column refer to the number of times each code was used throughout both datasets, and data from one participant could be coded more than once into the same code if, for example, they noted two separate concepts that would be covered by the same code in their response.

****INSERT TABLE 1 ABOUT HERE****

Worries and negatives

Social isolation was the most frequently reported negative/worry for adults with learning disabilities in both cohorts, and this included missing seeing their friends and family, and going out to their usual activities and clubs. Some people worried that they might never see some friends and family again:

"I am worried about the long term effects on my social life/social networks (will they still be there after the pandemic)." (Cohort 1, P209)

Some participants in Cohort 2 highlighted the difficulties of not having their family member live with them:

"He kept asking to come home, [...] the name of our village and 'home' - and I kept promising him, 'one day', 'soon', 'it won't be long' trying to keep his hope up. He went along with that, but sometimes he felt really impatient, shouted, broke things, hit out at people ... he was FED UP of waiting." (Cohort 2, P46)

Feelings of social isolation were often reported alongside a loss of routine, another commonly reported worry/negative for participants in both cohorts. The loss of services was also commonly reported as a worry/negative for both cohorts. This is consistent with other findings (Flynn et al., 2021) that access to and use of health and social care services significantly reduced for adults with learning disabilities across the UK between March 2020 and February 2021, with many people not receiving any services at all during that period.

The reduction of health and social care services was often reported alongside decreased health, wellbeing, and fitness of adults with learning disabilities.

"Less access to physical therapy like hydrotherapy and physiotherapy has meant his physical condition has deteriorated." (Cohort 2, P82)

This reduction was more frequently reported in Cohort 2 than in Cohort 1, which is consistent with quantitative findings from this study (Flynn et al., 2021).

Other reasons mentioned for poorer health and wellbeing included people exercising less but eating more, and anxiety about COVID-19 and the related restrictions leading to increased behaviours that challenge and poorer general mental health.

In Cohort 1, people with learning disabilities were more frequently worried about other people, getting COVID-19 than getting COVID-19 themselves. Sometimes these worries were interlinked:

“I don’t want to catch it, it might spread germs to other people.” (Cohort 1, P536)

Positives

For both cohorts, the most common code in the ‘Positives’ category was that nothing positive had happened because of COVID-19. Of the other responses, a frequently reported positive was that adults with learning disabilities had been able to be involved in online activities or had been able to improve their digital skills or digital access (e.g., they had been bought a new tablet to video call family).

While many participants who indicated that the health, wellbeing, and fitness of adults with learning disabilities had decreased during the pandemic, others in both cohorts indicated that they had become more active during the lockdowns (e.g., taking daily walks), or that they had not been able to easily access takeaways and other less healthy food, resulting in weight loss. In some cases, issues were highlighted with existing care plans after a period spent with family:

“My daughter’s care plan was reassessed as she was with me for 6 months and her health improved significantly with good, consistent personal care and attention to diet (milk free). I could not let her go back to supported living without an updated care plan to reflect her needs.” (Cohort 2, P193)

Sometimes increased exercise corresponded with spending time with family, and other important people:

“More cycling which I am enjoying - something that I had not cracked in the past. Now use a transportable fold up tricycle [...] with dad and really enjoying the exercise and seeing countryside.” (Cohort 1, P266)

A commonly reported positive was that many adults with learning disabilities had been able to spend more time with important people in their lives, in addition to the finding of social isolation in the ‘Worries/negatives’ category. Sometimes this was by telephone or video calls, with some people noting that the pandemic had meant that they had kept in touch more than before:

“Speaking to my family has been better, they have made an effort to keep in touch - this has worked both ways.” (Cohort 1, 485)

Some participants recognised that the pandemic had forced them to slow down, and that this had been beneficial. This related to not having to work all the time, being able to spend more time alone, and reflecting on their lives and what was important to them.

Discussion

This paper presents selected data from the first wave of the *Coronavirus and people with learning disabilities study* (Flynn et al., 2021). The most frequently reported worry/negative for both cohorts was social isolation, and the most commonly coded response in the ‘Positives’ category was that

nothing positive had happened because of COVID-19. Some of the most frequently reported worries/negatives and positives appeared to contradict each other (e.g., decreased or improved health, wellbeing, and fitness; and social isolation or more time spent with important people). There were also some differences between cohorts in the prevalence of codes within the categories, with some codes (e.g., social isolation; changes to or loss of routine; decreased wellbeing, health, or fitness) being more prevalent in Cohort 2, and others (e.g., digital inclusion; more time to spend on hobbies/interests; death, grief, and loss) being more prevalent in Cohort 1. These findings reflect the differing experiences for a heterogeneous population of adults with learning disabilities, with different living situations, access to technology, exercise, services, and support.

Some participants reported that they (Cohort 1), or the person they support (Cohort 2) had reconsidered their needs and/or life, as a result of the pandemic, and recognise that they may want to change some aspect of their lives going forward. Whilst a return to pre-pandemic life was desired by many participants, it cannot be assumed that this equates to an exact replication of pre-pandemic life and routines for all people with learning disabilities. Conversations about post-pandemic life with people with learning disabilities should, therefore, include discussions about any preferences for a “new normal”.

Although this dataset is the largest to date examining the experiences of adults with learning disabilities during the COVID-19 pandemic, there are limitations to be borne in mind. Data were collected across a three-month period across the UK, with some variations in restrictions over times and places. The way in which questions were presented to both cohorts (i.e., Cohort 1 were asked the question verbally by an interviewer, and Cohort 2 typed their response into an online survey) may have impacted the way in which participants answered the question, and interviewer recording of Cohort 1 participants’ answers were not always verbatim quotes.

Future pandemic planning must ensure that adults with learning disabilities are supported to maintain social contact with the people important to them, and that they should be supported to maintain, or improve, their health and wellbeing. This would include maintaining access to essential health and social care services, including day centres and community activities, providing a consistent routine. Some adults with learning disabilities may benefit from additional support to improve their digital confidence and access, which may in turn enable them to maintain some contact with family, friends, and support services/activities.

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Table 1. Coded worries/negatives and positives, including data about the prevalence of codes within each category

	Cohort 1 [number of times code was used ÷ total number of codes in category (%)]	Cohort 2 [number of times code was used ÷ total number of codes in category (%)]
Worries/negatives	1065	482
Social isolation	182 (17%)	176 (37%)
Worry about others generally or getting COVID-19	143 (13%)	1 (<1%)
Worries about if, how and when the pandemic will end	117 (11%)	8 (2%)
Worry about getting COVID-19	107 (10%)	6 (1%)
Changes to or loss of routine	74 (7%)	85 (18%)
Death, grief, and loss	67 (6%)	9 (2%)
Worries about staying safe	58 (5%)	1 (<1%)
Employment and education	56 (5%)	5 (1%)
Worries about COVID-19 generally	43 (4%)	5 (1%)
New rules or a new way of life	36 (3%)	33 (7%)
No worries/negatives	36 (3%)	3 (1%)
Loss of support, clubs, or services	34 (3%)	42 (9%)
Decreased health, wellbeing, or fitness	31 (3%)	86 (18%)
Missing important life events	24 (2%)	3 (1%)
Worries about the UK	24 (2%)	0 (0%)
Worries about the vaccine	23 (2%)	2 (<1%)
Worse financial situation	7 (1%)	0 (0%)
Worries about the world	3 (<1%)	0 (0%)
Everyday life	0 (0%)	17 (4%)
Positives	760	366
Nothing positive	223 (29%)	151 (41%)
Digital inclusion	98 (13%)	30 (8%)
More time spent with important people in their lives	77 (10%)	36 (10%)
More time to spend on hobbies or interests	57 (8%)	10 (3%)
Improved health, wellbeing, or fitness	40 (5%)	35 (10%)
Personal achievements	39 (5%)	5 (1%)
New relationships	37 (5%)	3 (1%)
Continuing employment or education	36 (5%)	2 (1%)
Slower pace of life or a better life balance	35 (5%)	25 (7%)
Improved living situation	33 (4%)	4 (1%)
Better financial situation	21 (3%)	3 (1%)
Everyday life	19 (3%)	24 (7%)
Learning new skills or practicing skills	13 (2%)	9 (2%)
Ability to stay safe	9 (1%)	13 (4%)
Increased independence	8 (1%)	13 (4%)
All going through it together	8 (1%)	0 (0%)
Discovered new local places	5 (1%)	0 (0%)
Having the vaccine	2 (<1%)	3 (1%)