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Tizard Learning Disability Review Trends Article

Health and social care access for adults with learning disabilities across the UK during the COVID-19 pandemic in 2020

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Abstract

Purpose

This paper presents data about access to health and social care services during the COVID-19 pandemic for adults with learning disabilities across England, Northern Ireland, Scotland and Wales.

Methodology

Data were collected directly from 621 adults with learning disabilities and through separate proxy reports by family carers and paid support staff of another 378 adults with learning disabilities. The data were collected between December 2020 and February 2021, and concerned the use of health and social care services since the start of the first COVID-19 national lockdown in March 2020.

Findings

Access to and use of health and social care services significantly reduced for adults with learning disabilities across the UK during the COVID-19 pandemic between March 2020 and February 2021, with many people not receiving any services at all during that period. Similar patterns were seen across England, Northern Ireland, Scotland and Wales. However, data suggest some variations between countries for some services.

Implications

Future pandemic planning must ensure that access to these essential services is not completely lost for adults with learning disabilities and their family carers, as it was in some cases during the COVID-19 pandemic in 2020.

Originality

This is the largest study about the impact of the COVID-19 pandemic on health and social care services for adults with learning disabilities 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, health, social care, access to services, COVID-19

Introduction

This paper provides an overview of access to health and social care services for people 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 are likely to either exclude or not identify people with learning disabilities (e.g., Understanding Society, 2021). Even nationally representative surveys are likely to have insufficient numbers of 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 the pandemic has had.

There are some limited data concerning access to health and social care services for adults with learning disabilities in the UK during the pandemic. These suggest reduced use of health and social care services (Mencap, 2020; The Scottish Commission for People with Learning Disabilities, 2020). However, these surveys have tended to be cross-sectional and largely completed by family carers of people with learning disabilities alone (e.g., Mencap, 2020), without the capacity to compare across the four nations of the UK.

This *Coronavirus and people with learning disabilities study* sought to address these issues by directly collecting data from adults with learning disabilities using direct interview methods, and focussing on key issues (including access to health and social care services) highlighted as important by partner organisations involving people with learning disabilities. It was also designed to consider country-specific outcomes.

Dataset

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 family carers and paid support staff of 378 adults with learning disabilities who could not take part in an interview with a researcher themselves (Cohort 2). In most 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); a group with high support needs who were unlikely to be represented in any large-scale experience surveys. Adults were defined as being aged 16 and over in England, Scotland and Wales, and 18 and over in Northern Ireland. A breakdown of where in the UK participants lived is presented in Table 1.

The data were collected between December 2020 and February 2021, with questions being asked about a variety of aspects of life during the COVID-19 pandemic (e.g., mental health, COVID-19-related questions, access to services, social contact). Full details of the survey methods and participants can be found in Flynn et al. (2021). The data presented in this paper focus on the use of health and social care services since the start of the first national COVID-19 lockdown in March 2020.

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

Results

Access to health services

Of all the adults with learning disabilities included in both cohorts, Table 2 reports the number and proportions of people who were regularly seeing different healthcare professionals before March 2020 and how many of these people were reported to have not seen the healthcare professionals at all between March 2020 and the time of data collection (December 2020-February 2021).

****INSERT TABLE 2 ABOUT HERE****

Across the UK generally adults with learning disabilities in Cohort 2 compared to Cohort 1 were more frequently reported to have seen these health professionals regularly prior to the first lockdown. Among those who would regularly see these health professionals, people with learning disabilities in Cohort 2 compared to Cohort 1 were less frequently reported to have seen a GP, community nurse, psychiatrist/clinical psychologist/counsellor, or ‘other’ (e.g., physiotherapist, occupational therapist, speech and language therapist) therapist at all between March and the data collection period (December 2020-February 2021). This was largely the case across all four countries of the UK, for all four types of health professional considered in the study. There are, however, some important differences across countries.

In Northern Ireland and Wales, a substantial proportion of people in both cohorts who would usually see their GP regularly were reported to have not seen them at all between March 2020 and the data collection period (December 2020-February 2021). In Northern Ireland, it was 41.9% and 57.1% for Cohorts 1 and 2 respectively. In Wales, it was 36.1% and 60.6% respectively.

In both Scotland and Wales, people in Cohort 2 who would usually see their community nurse regularly were far more frequently reported to have not seen them at all between March 2020 and the data collection period (December 2020-February 2021) (63.9% and 66.7% respectively) compared to people in Cohort 1 (28.9% and 29.6% respectively). The group who were most frequently reported to have seen a community nurse during this period were people in Cohort 1 in Northern Ireland. In England, people with learning disabilities in both cohorts were more frequently reported to have not seen ‘other’ therapists (55.6% and 66.7% respectively) than in the other three countries.

As well as access to health professionals being reduced or stopped completely, across the UK (between March 2020 and December 2020-February 2021) planned medical tests were reported to have been cancelled for 22% of people with learning disabilities in Cohort 1 and 28% of people with learning disabilities in Cohort 2. In this same timeframe, planned medical operations were reported to have been cancelled for 4% and 5% of people with learning disabilities in Cohort 1 and 2 respectively, and planned hospital appointments were reported as being cancelled for 23% of people with learning disabilities in Cohort 1 and 41% of people with learning disabilities in Cohort 2. Furthermore, between March 2020 and the data collection period (December 2020-February 2021) in Cohorts 1 and 2 across the UK, almost half of all people with learning disabilities who usually had an annual health check had not had one since the first national lockdown (46% and 48% respectively).

Access to social care services and formal supports

Of all the adults with learning disabilities included in both cohorts, Table 3 reports the proportions of people regularly receiving different formal supports before the first national COVID-19 lockdown in

March 2020 and how many of these people had not received these formal supports at all between March and the time of data collection (December 2020-February 2021).

****INSERT TABLE 3 ABOUT HERE****

There was a substantial reduction in the amount of support received by adults with learning disabilities in both cohorts across the UK between March 2020 and the data collection period (December 2020-February 2021). People with learning disabilities in Cohort 1 tended to be slightly less severely impacted than in Cohort 2. There was also variation between, and within, countries. For example, in Scotland 76.2% of people in Cohort 2 who regularly saw a social worker before March 2020 had not seen them at all during this period, compared with 36.5% of people in Cohort 1. People in both cohorts in Wales were the most frequently reported to have not attended a day service at all in this time period (71.1% and 70% respectively). Similarly people in both cohorts in Northern Ireland and Scotland were the most frequently reported to have not attended any community activities between March 2020 and the data collection period (December 2020-February 2021) (between 69.8% and 83.3%), and people in England and Wales in Cohort 1 were most frequently reported to have received no respite or short breaks (61.5% and 68.2% respectively).

Generally, Personal Assistants and Support Workers were still providing at least some support in the home. However, people in Cohort 2 (between 13.3% and 22.2%) compared to Cohort 1 (between 3.8% and 12.2%) were more likely to have had all home support stopped during this time period.

Discussion

This paper presents selected data from the first wave of the *Coronavirus and people with learning disabilities study* (Flynn et al., 2021), comparing access to health and social care services across the UK with two cohorts of adults with learning disabilities. There is a similar pattern of results across the two cohorts, with people in Cohort 2 being generally less frequently reported to have accessed health and social care services than people in Cohort 1 from the start of the first lockdown in March 2020 and the data collection period (December 2020-February 2021 – largely during a subsequent UK-wide lockdown). More adults with learning disabilities in Cohort 2 than people in Cohort 1 were regularly using these health and social care services before the first national lockdown in March 2020, and it is therefore likely that they would have had greater health and social care needs than people in Cohort 1.

The pattern of results was generally similar across the four countries of the UK, however, there was variation between countries in terms of which services were most frequently reported to have stopped particular services during this time period (e.g., community services in Northern Ireland and Scotland, short breaks/respite in England and Wales, day services in Wales). These differences are possibly reflective of pre-pandemic patterns of health and social care support and of the policy responses of individual countries to COVID-19 (e.g., lengthier full lockdowns, more severe local restrictions). The data also demonstrate differences within countries, potentially highlighting variation in how support was provided to people with learning disabilities depending on their level of need or vulnerability to serious illness if they got COVID-19.

Our dataset is the largest to date examining the impact of the COVID-19 pandemic on health and social care access for adults with learning disabilities. It must be acknowledged that the data were collected across a three month period, therefore some variability in experience might be expected. For example, people who were interviewed/surveyed in December 2020 may have been more likely to

have accessed services compared to people interviewed/surveyed in January and February 2021, during a period when lockdowns were in place across all four UK nations. We did not give a definition of “regular” access to health and social care services when participants were asked about their service use, so we cannot be certain that the interpretation of “regular” access was the same across all participants. We also must acknowledge that our samples in each country were not homogenous, and local restrictions and infection rates may have influenced the results. It is also possible that policy and practice varied between and within countries, with different service providers interpreting or implementing governmental guidance in slightly different ways. We also did not ask specifically about whether some services had moved online, only if people with learning disabilities had accessed them at all; this differentiation may not be reflected in the results. Finally, the numbers of people in each country who were accessing each service prior to the first lockdown differed, in some cases, substantially. This variation may have some impact on the way that these results are interpreted.

These data indicate that many health and social care services were completely lost for many adults with learning disabilities across the UK, and short breaks/respite was lost for many family carers. This loss is likely to have exacerbated the social isolation and health inequalities that were faced by adults with learning disabilities (Chadwick, Wesson & Fullwood, 2013; Emerson & Hatton, 2014) prior to access to services being reduced or suspended due to COVID-19. Research should seek to understand what impact reduced access to services has had on the current and future physical and mental health of people with learning disabilities, including feelings of social isolation. It is evident, therefore, that future pandemic planning must ensure that access to these essential services is maintained for adults with learning disabilities, and their family carers, in the UK in the event of another lockdown or pandemic.

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Table 1. Where people who took part in the study lived

	Cohort 1 (n)	Cohort 2 (n)
England	181	126
Northern Ireland	127	62
Scotland	159	113
Wales	149	77

Table 2. Proportion of people with learning disabilities who saw each healthcare professional regularly before the March 2020 national COVID-19 lockdown, and who had then not seen them at all between March 2020 and December 2020-February 2021

		Cohort 1 [n (%) used to regularly see]	Cohort 1 (% of those who used to regularly see, have not seen at all since lockdown)	Cohort 2 [n (%) used to regularly see]	Cohort 2 (% of those who used to regularly see, have not seen at all since lockdown)
GP					
	<i>England</i>	95 (52.5)	29.5	69 (54.8)	34.8
	<i>Northern Ireland</i>	43 (33.9)	41.9	28 (45.2)	57.1
	<i>Scotland</i>	66 (41.5)	25.8	40 (35.4)	42.5
	<i>Wales</i>	92 (40.9)	36.1	33 (42.9)	60.6
Community nurse					
	<i>England</i>	51 (28.2)	21.6	42 (33.3)	45.2
	<i>Northern Ireland</i>	11 (8.7)	18.2	16 (25.8)	37.5
	<i>Scotland</i>	45 (28.3)	28.9	36 (31.9)	63.9
	<i>Wales</i>	27 (18.1)	29.6	24 (31.2)	66.7
Psychiatrist/clinical psychologist/counsellor					
	<i>England</i>	37 (20.4)	37.8	34 (27.0)	52.9
	<i>Northern Ireland</i>	23 (18.1)	39.1	21 (33.9)	52.4
	<i>Scotland</i>	34 (21.4)	32.4	22 (19.5)	50.0
	<i>Wales</i>	33 (22.1)	30.3	24 (31.2)	58.3
Other therapist					
	<i>England</i>	27 (14.9)	55.6	48 (38.1)	66.7
	<i>Northern Ireland</i>	7 (5.5)	42.9	13 (21.0)	30.8
	<i>Scotland</i>	36 (22.6)	52.8	50 (44.2)	66.0
	<i>Wales</i>	22 (14.8)	50.0	23 (29.9)	60.9

Table 3. Proportion of people with learning disabilities who used different formal supports regularly before the March 2020 lockdown, and who had then not use them at all between March 2020 and December 2020-February 2021

	Cohort 1 [n (%) used to receive regularly]	Cohort 1 (% of those who used to receive regularly, have not received at all since lockdown)	Cohort 2 [n (%) used to receive regularly]	Cohort 2 (% of those who used to receive regularly, have not received at all since lockdown)
Day services				
<i>England</i>	67 (37.0)	55.2	63 (50.0)	58.7
<i>Northern Ireland</i>	55 (43.3)	36.4	45 (72.6)	37.8
<i>Scotland</i>	57 (35.8)	54.4	67 (59.3)	70.1
<i>Wales</i>	45 (30.2)	71.1	40 (51.9)	70.0
Community activities				
<i>England</i>	151 (83.4)	54.3	106 (84.1)	84.9
<i>Northern Ireland</i>	106 (83.5)	69.8	49 (79.0)	77.6
<i>Scotland</i>	143 (89.9)	53.8	87 (77.0)	82.8
<i>Wales</i>	130 (87.2)	71.5	60 (77.9)	83.3
Further education				
<i>England</i>	22 (12.2)	54.5	26 (20.6)	38.5
<i>Northern Ireland</i>	34 (26.8)	32.4	16 (25.8)	50.0
<i>Scotland</i>	21 (13.2)	42.9	22 (19.5)	59.1
<i>Wales</i>	28 (18.8)	78.6	17 (22.1)	41.2
Going out with Personal Assistants/Support Workers				
<i>England</i>	97 (53.6)	15.5	103 (81.7)	25.2
<i>Northern Ireland</i>	42 (33.1)	33.3	38 (61.3)	42.1
<i>Scotland</i>	92 (57.9)	21.7	76 (67.3)	26.3
<i>Wales</i>	77 (51.7)	31.2	55 (71.4)	30.9

Respite/Short breaks				
away from home				
<i>England</i>	13 (7.2)	61.5	44 (34.9)	52.3
<i>Northern Ireland</i>	20 (15.7)	45.0	18 (29.0)	61.1
<i>Scotland</i>	11 (6.9)	45.5	48 (42.5)	68.8
<i>Wales</i>	22 (14.8)	68.2	27 (35.1)	70.4
Personal Assistants				
/Support Workers helping them at home				
<i>England</i>	114 (63.0)	4.4	90 (71.4)	13.3
<i>Northern Ireland</i>	53 (41.7)	3.8	28 (45.2)	21.4
<i>Scotland</i>	94 (59.1)	7.4	64 (56.6)	18.8
<i>Wales</i>	82 (55.0)	12.2	36 (46.8)	22.2
Social Worker visits				
<i>England</i>	97 (34.8)	42.9	34 (27.0)	73.5
<i>Northern Ireland</i>	55 (43.3)	50.9	27 (43.5)	66.7
<i>Scotland</i>	52 (32.7)	36.5	42 (37.2)	76.2
<i>Wales</i>	54 (36.2)	51.9	31 (40.3)	64.5