February 2022

POLICY BRIEFING

CORONAVIRUS AND PEOPLE WITH LEARNING DISABILITIES IN ENGLAND

INTRODUCTION

The Covid-19 pandemic has had wide-reaching impacts across the world. In addition to illness and loss of life, lockdowns and social distancing restrictions have impacted on people's lives socially and economically. For people with learning disabilities, existing inequalities in health, wellbeing, employment and economic circumstances, along with the changes to routines and separation from family and friends, were known at an early stage of the Covid-19 pandemic to be challenges for both people with learning disabilities and the people who support them. This briefing paper highlights the policy implications of the Covid-19 pandemic in England, drawing on the Coronavirus and People with Learning Disabilities Study and the experiences and reflections of people with learning disabilities, family members and those supporting people.

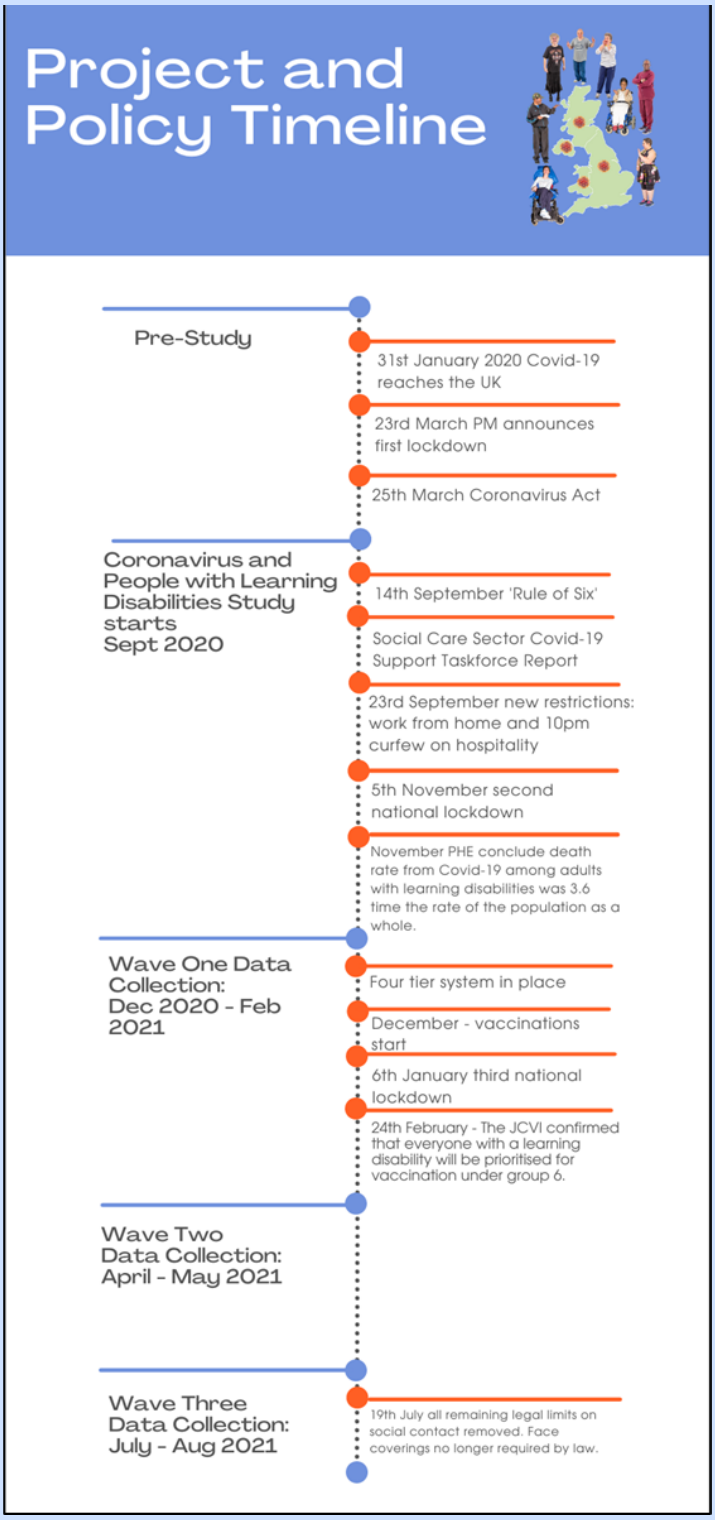
The Coronavirus and People with Learning Disabilities Study

The Coronavirus and People with Learning Disabilities Study directly interviewed (by video call or telephone) adults with mild/moderate learning disabilities at three time points over 12 months (Cohort 1). There was also an online survey at the same time points with family members or paid carers of people with severe/profound learning disabilities (Cohort 2). The three waves of data collection took place in December 2020 - February 2021; April – May 2021; and July - August 2021. In total, 692 people with mild/moderate learning disabilities across the UK were interviewed (188 in England) and 473 (159 in England) family members/paid carers completed an online survey. At each wave of data collection, interview and survey questions were developed in partnership with the project's collaborating organisations across the UK. In England, these were Learning Disability England (LDE) and PMLD Link.

Findings for England are presented in this brief, but people's experiences were similar across the UK. The study covered a wide range of topics, but in England, people with learning disabilities and family members have identified the issues in this policy brief as being the most important for policy and practice.

POLICY TIMELINE

The timeline below illustrates the context in which each of the three waves of data collection took place. Policy decisions that were key for people with learning disabilities and lockdown dates that took place in England are marked on the timeline.



Project and Policy Timeline

Pre-Study

31st January 2020 Covid-19 reaches the UK

23rd March PM announces first lockdown

25th March Coronavirus Act

Coronavirus and People with Learning Disabilities Study starts Sept 2020

14th September 'Rule of Six'

Social Care Sector Covid-19 Support Taskforce Report

23rd September new restrictions: work from home and 10pm curfew on hospitality

5th November second national lockdown

November PHE conclude death rate from Covid-19 among adults with learning disabilities was 3.6 time the rate of the population as a whole.

Wave One Data Collection: Dec 2020 - Feb 2021

Four tier system in place

December - vaccinations start

6th January third national lockdown

24th February - The JCVI confirmed that everyone with a learning disability will be prioritised for vaccination under group 6.

Wave Two Data Collection: April - May 2021

Wave Three Data Collection: July - Aug 2021

19th July all remaining legal limits on social contact removed. Face coverings no longer required by law.

EMPLOYMENT AND MONEY

In England, levels of paid employment and volunteering among people with learning disabilities have not returned to pre-pandemic levels.

For people with learning disabilities in Cohort 1 35% had a paid job before the first lockdown - by August 2021 this had decreased to 30%. At Wave 1, 9% of Cohort 1 were furloughed and this had reduced to 1% by Wave 3. For people with learning disabilities in Cohort 2, only 5% had a paid job before lockdown and this decreased to 2% by August 2021.

People who had a volunteering role declined from 48% to 28% between the first lockdown and August 2021 for people in Cohort 1 and from 13% to 6% for people in Cohort 2.

Around a quarter of people with learning disabilities in Cohort 1 were worried about the amount of money coming in (25% at Wave 1 and 28% at Wave 3). In Cohort 2, 89% in Wave 1 had enough money - this decreased to 81% in Wave 3.

Recommendations

There is an urgent need to increase the number of people with learning disabilities in stable paid employment beyond pre pandemic levels. This should include effective supported employment and provision of work experience placements through education settings to support people in preparation for employment.

A proactive approach is needed to increase meaningful volunteering opportunities. This is one way to support people to be a valued part of their local communities.

Benefits need to be flexible to quickly accommodate part-time and short-term paid employment without penalising people for being employed. The process needs to be easy to navigate to alleviate fears of benefits being reduced.

MENTAL HEALTH AND WELLBEING

Loneliness was a problem for around half of the people with learning disabilities in Cohort 1. The percentage of those who said they were lonely at least some of the time was consistent across all three waves of the study (Wave 1, 45%; Wave 2, 53%; Wave 3, 43%).

At Wave 1, almost a third of people (32%) in Cohort 1 had felt worried or anxious often or always. By Wave 3 this had reduced but was still almost a quarter of people (24%) in Cohort 1 and over a quarter of people (28%) in Cohort 2. Similarly, a quarter of people with learning disabilities (25%) in Cohort 1 said they had felt sad or down often or always. By Wave 3 this had reduced but was still 17% of people.

By July/August 2021, only 31% of people with learning disabilities in Cohort 1 and 19% of people with learning disabilities in Cohort 2 had gone back to everywhere they used to go before the pandemic. This was a particular concern for people with profound and multiple learning disabilities (PMLD). By July/August 2021, only 9% of people in Cohort 1 and 4% of people in Cohort 2 said their life had gone back to normal.

There has been a detrimental impact on both the mental and physical wellbeing of carers. Across all three waves of the study, carers have consistently reported that their caring role has led to feelings of tiredness (Wave 1, 61%; Wave 2, 42%; Wave 3, 46%); general feelings of stress (Wave 1, 61%; Wave 2, 37%; Wave 3, 41%); and disturbed sleep (Wave 1, 56%; Wave 2, 36%; Wave 3, 38%).

Recommendations

The response to the pandemic needs to take account of the impact on people's social and emotional wellbeing. People with learning disabilities were already often isolated and lonely. There is a need for a proactive approach to increasing opportunities for supported activities to connect people. One example is funding for self-advocacy groups to provide social activities that increase social connections and in turn improve social and emotional wellbeing.

Community-based mental health services that are accessible to people with learning disabilities need to be radically improved to provide skilled support to understanding mental health.

There is an urgent need for more peer and emotional support for family carers.

The current crisis in workforce issues needs to be addressed due to the impact on people who need good quality care. There is a need for proper support as promised in the Care Act.

SOCIAL CARE SERVICES

Most social care services have not returned to the levels they were at before the pandemic. People with learning disabilities in Cohort 1 who went to a day service reduced from 37% of people before the pandemic to 25% at Wave 3 and from 51% to 30% for people with learning disabilities in Cohort 2. People in Cohort 1 who were going out to community activities reduced from 83% pre-pandemic to 49% at Wave 3 of the study and from 84% to 34% for people with learning disabilities in Cohort 2.

Before the pandemic, 64% of people with learning disabilities in Cohort 1 had personal assistants (PAs) or support workers helping at home; this reduced to 60% at Wave 2 and 55% at Wave 3. For people with learning disabilities in Cohort 2, 73% had PAs or support workers helping them before the pandemic; by Wave 3 this had reduced to 61%. Pre-pandemic, 84% of people in Cohort 2 had been out of the house with a PA/support worker, this had reduced to 67% at Wave 3. Additionally, the use of short breaks / respite for people with learning disabilities in Cohort 2 reduced from 36% pre-pandemic to 12% at Wave 3.

Only just over half (54%) of people with learning disabilities in Cohort 1 said they got roughly the same amount of support in Wave 3 as before the pandemic (15% got less, 9% got more). For people with learning disabilities in Cohort 2, 41% said they got roughly the same amount of support; nearly half (47%) got less and 7% got more.

Recommendations

Not everyone was getting enough support before the pandemic – people should be getting at least that level of support back not less. Without support people will become more lonely and experience mental health concerns.

There is a need to reform and replace service gaps created by the pandemic with alternative services and programmes. People must be given the opportunity to identify their new priorities and preferences and reformed services should reflect this. For example, for some people with learning disabilities day services are considered outdated and different support is needed to fill that gap - while others rely on them.

People should be asked about individual preferences regarding online and face to face services and activities alongside a recognition that these individual preferences can change over time.

HEALTH AND HEALTH SERVICES

Across all three waves of the study, only just over half of people with learning disabilities in Cohort 1 rated their health as good (Wave 1, 54%; Wave 2, 58%; Wave 3, 57%). For Cohort 2, only 45% in Wave 1 and 44% in Wave 2 rated the health of the person they support as good. At Wave 3 this had dropped to 21%.

By July/August 2021, less than half of people in Cohort 1 (44%) had had an annual health check in person or by phone or video call (40% said no or don't know and 17% said they did not normally have one). For people in Cohort 2, 43% had had a check in person or by phone or video call (49% said no or don't know and 8% said they did not normally have one).
At Wave 1, 53% of Cohort 1 and 46% of Cohort 2 said they used to see their GP regularly before the pandemic. At Wave 3, only 18% of Cohort 1 and 13% of Cohort 2 had seen their GP in person in the previous 4 weeks - 26% of Cohort 1 and 21% of Cohort 2 had seen them by telephone or video call.

Similarly, access to other health professionals has not returned to pre-pandemic levels. At Wave 1, 28% of Cohort 1 and 31% of Cohort 2 said they used to see a community nurse regularly before the pandemic. At Wave 3, this has gone down to 20% for Cohort 1, and 24% for Cohort 2. At Wave 1, 20% of Cohort 1 and 26% of Cohort 2 said they used to see a psychiatrist, clinical psychologist or counsellor regularly before the pandemic. At Wave 3, this has gone down to 15% in for Cohort 1, and 9% for Cohort 2.

Recommendations

Ensuring that high quality annual health checks take place is vital for keeping people with learning disabilities healthy. Annual health checks must lead to documented health service actions that are followed up by GPs to make sure that they happen.

To facilitate annual health checks, access to GPs must be more straightforward. Complex appointment booking systems are barriers. People with learning disabilities need more time with GPs and to be prioritised in appointment waiting lists.

People will have delayed seeking help for both physical and mental health concerns or problems. There needs to be an urgent improvement on pre-pandemic levels of support from health professionals for people with learning disabilities to accommodate this.

DIGITAL INCLUSION

Digital inclusion has been important during the Covid-19 pandemic primarily to support social connections. Internet access was widespread for people in Cohort 1 in England (90% in Wave 1; 95% in Wave 3). Internet use was less common for people with learning disabilities in Cohort 2; in Wave 3, only 41% had access to the internet at home and only 48% had access to a device to use the internet with.

People with learning disabilities in both cohorts most commonly used the internet for being with friends and family online. In July/August 2021, the majority (66%) of people with learning disabilities in Cohort 1 still enjoyed taking part in online activities.

Recommendations

Some people with learning disabilities are still not going out into the community as much as they did before the pandemic. Online connections can be an important way to feel included and connected to people. People need to be supported to be able to continue developing digital skills. Care assessments and packages should routinely include the use of IT and access to online communities.

Support staff need to be provided with training to ensure they can provide appropriate digital support.

Technology resources that suit individual preferences should be made freely available or significantly more affordable to ensure digital inclusion of all people with learning disabilities.

INFORMATION

Most people with learning disabilities and their family members or paid carers (>68% across both cohorts throughout the study) got information about the changes to Covid-19 rules from the television (including general news programmes and televised Government briefings). However, some people with learning disabilities in Cohort 1 did not always find it easy to find good information (33% said it had not been easy in Wave 1; 21% in Wave 2 and 25% in Wave 3). Some people were not sure or did not know what the rules were where they lived about coronavirus and social distancing (Wave 1, 18%; Wave 2, 12%; Wave 3, 15%). Across all three waves of the study, approximately a quarter of carers reported that it was difficult to find accurate information about how Covid-19 affects them

Recommendations

Mainstream media should continue to be a focus for giving and updating people with official communication from the Government.

Important national Government information must be made available in a range of accessible formats. Appropriate easy-read materials, videos and other accessible formats should accompany new information. Organisations who rapidly respond to crisis situations by providing and sharing good accessible information should be funded by the Government to do this.

Families of people with the greatest support needs must not be forgotten when information is shared.

EXPERIENCES OF PEOPLE WITH GREATER SUPPORT NEEDS

People with PMLD were more likely than other people in Cohort 2 to get less support at Wave 3 than before the pandemic.

Family members of people with PMLD were more likely than the family members or paid carers of other people in Cohort 2 to report on the impact of their caring role on their own health in terms of feeling depressed, being short-tempered/irritable and loss of appetite.

Some people with learning disabilities have been shielding for extended periods. For people with learning disabilities in Cohort 2 21% of people were still shielding at Wave 3 (shielding went from 48% at Wave 1, to 39% at Wave 2 to 21% at Wave 3).

Recommendations

Families have sometimes struggled to cope with reduced levels of support, resulting in negative impacts on their physical and mental wellbeing. The pressure on families is unsustainable and support services for people with PMLD and their families should be urgently improved. The family carers of people still shielding need support; opportunities to access respite care when possible should be prioritised.

Services need to reconnect with people who are still shielding to reassess what people need. There is an overall need for more support.

FOR FURTHER INFORMATION:

Professor Chris Hatton, Department of Social Care and Social Work, Manchester Metropolitan University. Email: C.Hatton@mmu.ac.uk

Learning Disability England https://www.learningdisabilityengland.org.uk/ Email: info@LDEngland.org.uk

Funding

This research was funded by UK Research and Innovation (Medical Research Council), and supported by the Department for Health and Social Care (National Institute for Health Research) as part of the UKRI-DHSC COVID-19 Rapid Response Rolling Call. UKRI: MR/V028596/1 NIHR: COV0196

This policy brief draws on independent research funded by the Department for Health and Social Care (DHSC) (National Institute for Health Research; NIHR) and UK Research and Innovation (UKRI) (Medical Research Council; MRC). The views expressed in this presentation are those of the authors and not necessarily those of DHSC, NIHR, UKRI or MRC.