

The experiences of family carers of people with learning disabilities during Covid-19 and good practice recommendations for the 'new normal'

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Background

Over five years have passed since the first national lockdown in the UK during the Covid-19 pandemic. Despite this, it is still important to learn from the experiences of family carers of people with learning disabilities during this time for two main reasons:

- 1) To provide insight into any bigger issues regarding support for family carers of people with learning disabilities that were amplified during lockdown.
- 2) To understand more about how families can be better supported in the case of any future pandemics, or similar circumstances.

There is plenty of evidence highlighting the best support for people with learning disabilities^{1,2,3} and their families. This includes ensuring support is person-centred, co-produced and consistently updated to guarantee that

¹ National Institute of Health and Care Excellence (NICE). (2018). *Learning disabilities and behaviour that challenges: service design and delivery*. NICE. <https://www.nice.org.uk/guidance/ng93/resources/learning-disabilities-and-behaviour-that-challenges-service-design-and-delivery-pdf-1837753480645>

² NICE. (2015). *Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges*. NICE. <https://www.nice.org.uk/guidance/ng11/resources/challenging-behaviour-and-learning-disabilities-prevention-and-interventions-for-people-with-learning-disabilities-whose-behaviour-challenges-pdf-1837266392005>

³ Challenging Behaviour Foundation. *Best Practice*. Challenging Behaviour Foundation. <https://www.challengingbehaviour.org.uk/what-we-do/sharing-best-practice/best-practice-examples/>

the most appropriate support is provided as the individual's needs or circumstances change. Additionally, the United Nations Convention on the Rights of the Child⁴ emphasises the rights of disabled children to have effective access to a range of services and support that allows them to participate in society as much as possible.

However, this is often not implemented and families of people with learning disabilities experience preventable disadvantages in accessing high quality care⁵ for their relatives who are subjected to unnecessary distress as a result. Even over five years following the first national lockdown in the UK, it remains evident that more needs to be done to utilise knowledge gained during the pandemic to improve the quality of support for people with learning disabilities and their families.

Research on what people with family carers and their relatives with a learning disability found helpful or unhelpful during the pandemic may be useful to understand what support would be helpful to implement, improve, or maintain going forward. Therefore, this report will share the

⁴ UNICEF. (1990). The United Nations Convention on the Rights of the Child. Available from: https://downloads.unicef.org.uk/wp-content/uploads/2010/05/UNCRC_united_nations_convention_on_the_rights_of_the_child.pdf

⁵ Care Quality Commission (CQC). (2023, October 30). *State of Care 2022/23*. CQC. <https://www.cqc.org.uk/publications/major-report/state-care/2022-2023>

findings of a study completed by the Challenging Behaviour Foundation (CBF), the Sharland Foundation Developmental Disabilities Applied Behavioural Research and Impact Network (SF-DDARIN) and the Tizard Centre, University of Kent.

This study explored the experiences of family carers of people with learning disabilities during the Covid-19 pandemic. The information shared by family carers about their experiences during the pandemic, both positive and negative, may help us understand what went well or what was challenging for them and their relative, and how this information can be utilised to improve support in the future.

The findings can be shared with policymakers, professionals, and services to identify potential changes to limit challenges and disruptions in support and care in both everyday life and in the context of a future unprecedented circumstance (e.g., another pandemic). The findings can be combined with existing knowledge of best practice for people with learning disabilities, to create a broader understanding of how best to support family carers and their relatives with a learning disability.



What we did

In 2020, family carers of people with learning disabilities living in the UK were invited to take part in an online interview about their, and their relatives experiences during the pandemic. These interviews took place between the first and second national UK lockdown during the Covid-19 pandemic⁶, with some interviews taking place after the second national lockdown was announced.

Who took part?

Overall, 11 family carers of 12 people with learning disabilities living in the UK completed an interview. Their relatives were mostly adults (80%) with a total age range of 9–33 years old. All of their relatives had a learning disability, and some had additional diagnoses including autism, Down syndrome, epilepsy, physical disability, post-traumatic stress disorder, pica, and/or attention deficit hyperactivity disorder.

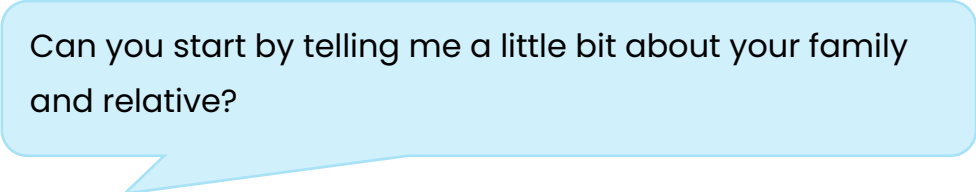
⁶ Sherrington, A. (2022, July 25). *2 Years of COVID-19 on GOV.UK*. UK Government. <https://gds.blog.gov.uk/2022/07/25/2-years-of-covid-19-on-gov-uk/>

How were the interviews organised?

The interview questions were designed to prompt a conversation with family carers regarding their and their relatives' Covid-19 experiences. The interviewers facilitated the conversation using pre-prepared visual aid with prompts for areas to discuss and a rating scale (see Figure 1). The interview was split into five sections:

1. Introduction

Introductions included discussing the interview approach and asking open questions around the family carer and their relative with a learning disability.

A light blue speech bubble with a tail pointing towards the bottom left. Inside the bubble, the text reads: "Can you start by telling me a little bit about your family and relative?"

Can you start by telling me a little bit about your family and relative?

2. Areas that are important to and for their relative

For this section, the interviewer shared their screen in Zoom to show the family carer the visual aid. The visual aid had 20 "topics" that may be important to or for the person with a learning disability, such as family, independence, communication, health, and professionals (see Figure 1). Figure 2 outlines how the visual aids were categorised for this question.

Figure 1 – Example of a visual aid screen

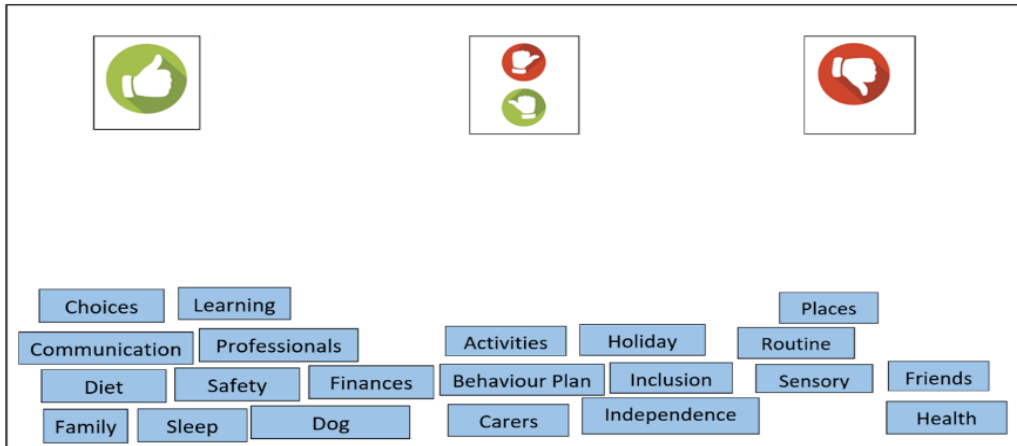





Figure 2 – Table showing how the visual aid screens were categorised in section 2

<p>Thumbs up/important (left)</p> 	<p>Family carers were asked to place topics on the left-hand side if they thought they were important to or for their relative with a learning disability.</p>
<p>Neither important nor unimportant/ not sure (middle)</p> 	<p>Family carers were asked to place topics in the middle if they thought they were neither important nor unimportant for their relative with a learning disability, or if they were not sure about their importance.</p>
<p>Thumbs down/not important (right)</p> 	<p>Family carers were asked to place topics on the right-hand side if they thought were not important to or for their relative with a learning disability.</p>

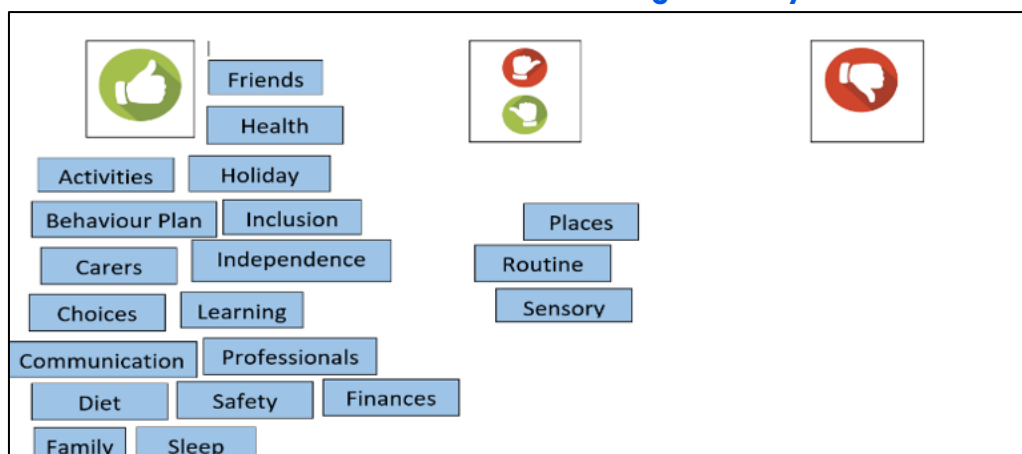


Family carers were asked how important they thought each of the 20 “topics” were to or for their relative. They were asked where to put each on the visual aid (see Figure 3 for an example) and discuss these with the interviewer. This step was used to help the researcher understand what “topics” the rest of the interview should focus on.

Family carers were then asked if there was anything else that was important to or for their relative. If they responded ‘yes’, the interviewer added these to the visual aid and discussed them with the family carer.

What is important to and for your relative?

**Figure 3 – Example visual aid of important topics
for their relative with a learning disability**





3. Life during lockdown

This section explored the experiences of the family carer's relative with learning disabilities during the pandemic, particularly lockdown, using another visual aid (see Figure 4). For this, only the "topics" family carers identified as being important to or for their relative in section 2 were discussed (i.e., those placed on the left-hand side of the visual aid). Figure 5 outlines how the visual aids were categorised for this question.

Family carers were asked to place each "topic" they deemed important (e.g., sleep, choices, family) on the visual aid to indicate what it was like during lockdown for their relative (for an example see Figure 5) and discuss these with the interviewer in more detail.

What has support for your relative been like during lockdown?

Figure 4 – Example visual aid of how life was like during lockdown for their relative with a learning disability

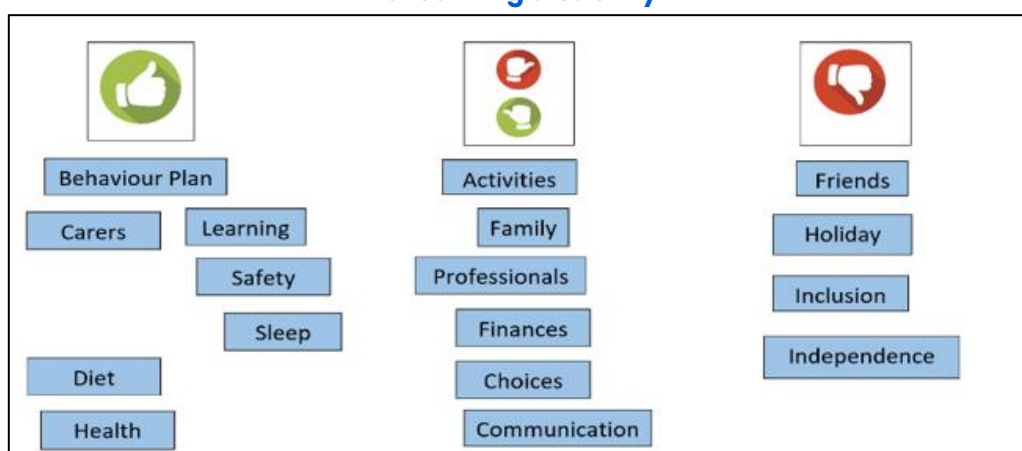





Figure 5 - Table showing how the visual aids were categorised in section 3

<p>Thumbs up/went well (left)</p> 	<p>Family carers were asked to place topics on the left-hand side if they thought they went well for their relative with a learning disability.</p>
<p>Neither well nor not well/not sure (middle)</p> 	<p>Family carers were asked to place topics in the middle if they thought they went neither particularly well or not well for their relative with a learning disability, or if they were not sure about how they went.</p>
<p>Thumbs down/did not go well (right)</p> 	<p>Family carers were asked to place topics on the right-hand side if they thought it did not go well for their relative with a learning disability.</p>

4. Looking forward

The fourth section of the interview explored what could help support family carers and their relative with a learning disability in the future once lockdown(s) ended.

Is there anything you have realised during this period that could help support you and you relative in the future once lockdown ends?

5. Ending

Before ending the interview, the interviewer asked if there was anything else the family carer would like to share about their relatives' support during the pandemic or thinking to the future. The interviewer then supported the family carer to identify up to three key points for the following:

- Key topics that are important for their relative's support
- Key challenges of lockdown(s) for supporting their relative
- Anything that helped the family carer during this period (i.e., lockdown, pandemic)
- Surprises or things that have gone well during this period
- Hopes and needs for their relative's support in the future

Is there anything else you'd like to tell me about support for your relative during this time, or thinking to the future?

How were the interview findings shared?

Initial findings of this analysis were shared at a [Challenging Behaviour National Strategy Group \(CB-NSG\) meeting in October 2020](#). After more interviews were completed, they were all analysed together using framework analysis to identify common key areas mentioned by a majority of family carers. Framework analysis involves reading the interviews and picking out any recurring 'themes' that are mentioned by multiple family carers.

What we found out from the interviews

Key points

- Lots of topics were identified by family carers as being important to or for their relative with a learning disability. The topics most family carers said were important included activities, communication, safety, diet and carers
- Life during lockdown was varied for family carers and their relatives with a learning disability
- Key areas identified from the interviews included: 'Relationships', 'Support workers', 'Services', and 'Disruption'
- Family carers discussed positive and negative experiences of each area

Visual Aids

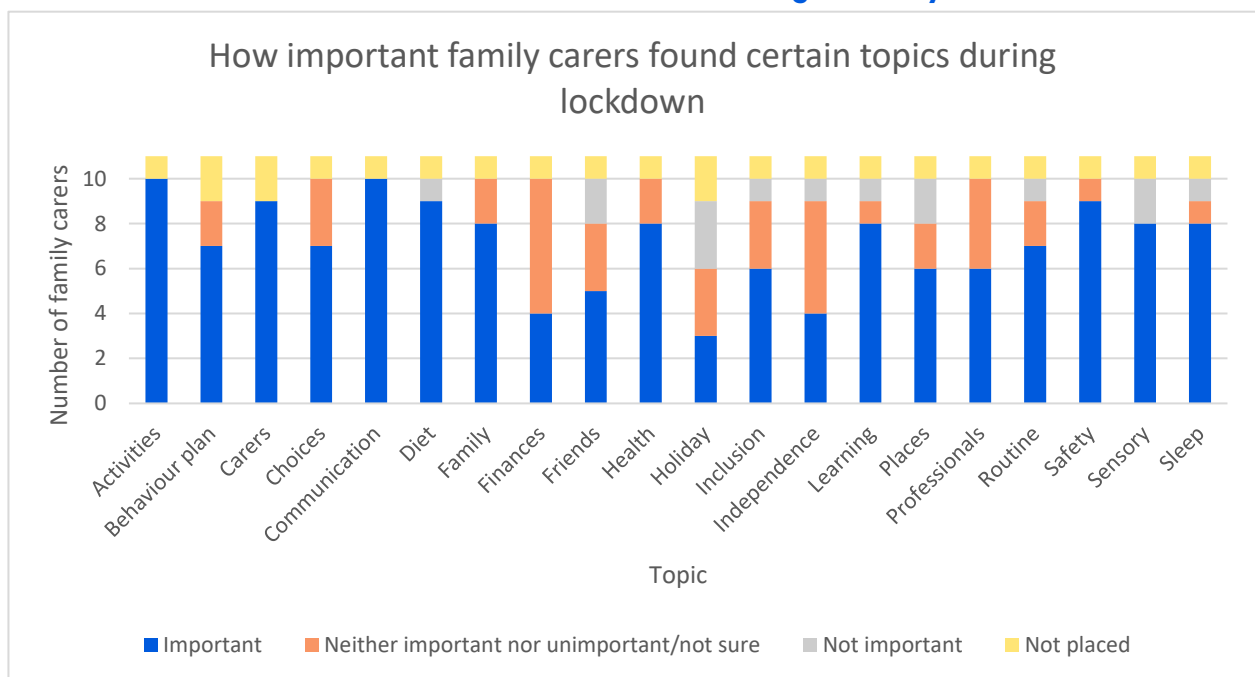
Important topics

During the first visual aid, each of the 20 "topics" were deemed to be important to or for their relative with a learning disability by between 3 to 10 of the 11 family carers (see Figure 6). One family carer decided to not place any topics on the visual aid.

Topics deemed to be important by most of the family carers were activities and communication (10 family carers (91%) thought these were important

to/for their relative), followed by safety, diet, and carers (9 family carers (82%) thought these were important to/for their relative). Family carers also identified an additional 26 topics that were important to or for their relative including respite, school, happiness, and pets.

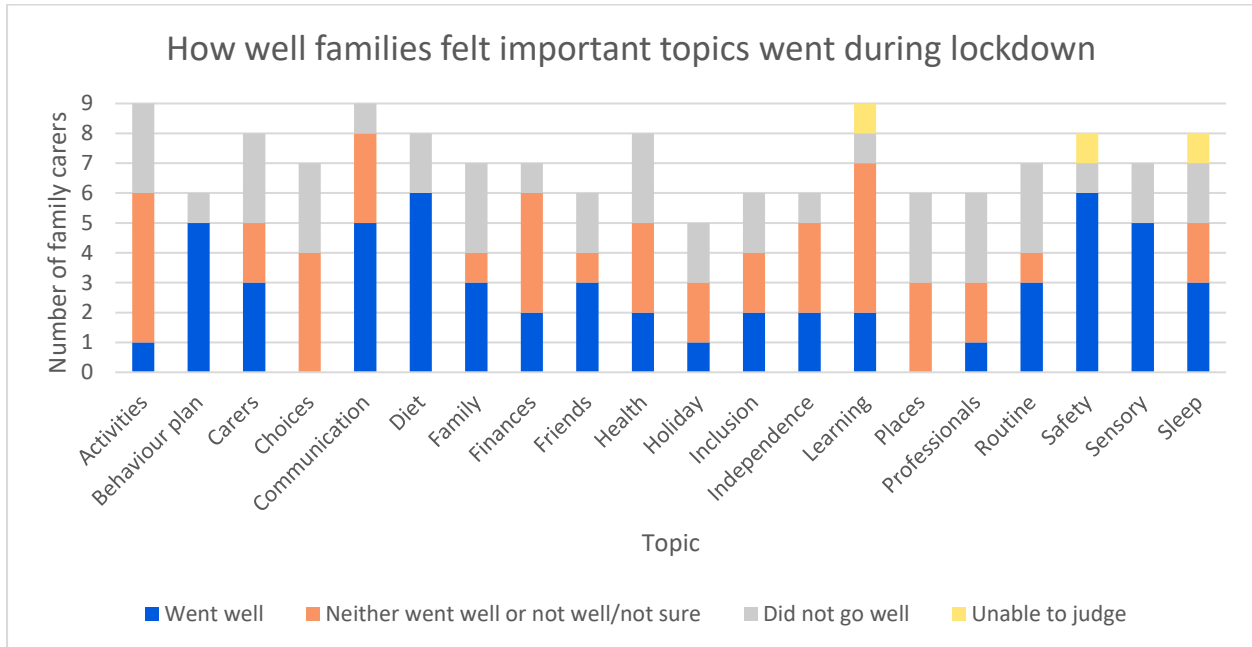
Figure 6 – A graph showing how important family carers thought different topics were to or for their relative with a learning disability



Life during lockdown

During the second visual aid, family carers reported how the important “topics” had gone for their relative during lockdowns, and responses were varied (see Figure 7). An additional 34 topics were discussed by family carers at this stage regarding their relatives' experiences during lockdown.

Figure 7 – A graph showing how well family carer’s thought important topics had gone for their relative with a learning disability during lockdowns



Key areas identified as being relevant to the lockdown experience

Four overarching key areas regarding the experiences of the family carers relatives’ experiences during the pandemic and lockdowns were identified from the interviews with family carers. The key areas were:

- ‘Relationships’, which 8 family carers (73%) discussed in their interviews.
- ‘Support workers’ (discussed by 10 family carers, 91%)
- ‘Services’ (discussed by 10 family carers, 91%)
- ‘Disruption’ (discussed by all 11 family carers, 100%)

Relationships

The 'relationships' key area included how the pandemic affected the family carers' relatives' relationships with loved ones, and how new methods of communication were used throughout the pandemic (e.g., video calls) to ensure relationships were supported during a time where in-person visits were prohibited. Some family carers had positive experiences due to being at home more thus being able to spend more time speaking to loved ones. Conversely, one family carer described how the pandemic helped them realise they were personally happier not seeing some individuals throughout lockdown.

"I think that has benefited [relative with learning disability], you know the ability for him to be able to pick up the phone at different times".

For others, the pandemic had a negative impact on relationships, as family carers could not visit their relatives and felt as though they, as family carers, would have benefitted from additional support from family members. The inability to visit loved ones was replaced with other methods of communication for some, such as posting gifts or engaging in new methods of remote communication such as virtual calls.

"It's really hard when you're used to seeing someone a lot and you know that they rely on that for their mental health, and maybe you do too. And suddenly that isn't possible".

Support Workers

The 'support workers' key area included experiences families had with support staff, and the impact that they had on families' circumstances. Many family carers praised support workers' aid throughout the pandemic and their efforts to ensure that their relatives with learning disabilities and their family still received support. Some ways in which support staff helped family carers' relatives with learning disabilities during the pandemic included supporting them to wear a mask or arranging virtual calls.

"[Support worker] did some online calls to [relative with learning disability] which was really successful".

In contrast, other family carers mentioned an absence and lack of communication from support workers during the pandemic, with some leaving the support setting entirely. Family carers also discussed issues they had experienced with support staff within residential settings supporting their relative with learning disabilities, including enforcing blanket restrictions across settings.

"One of our carers [support worker] decided not to come back to work with us. That's a real loss for us".

Services

The 'services' key area included family carers' experiences of communicating with services, and their ability to access services during the pandemic and lockdowns. Family carers mentioned ways that services adapted to support their relatives' needs during the pandemic. This included financial support, which was used to support their relative in other ways whilst services were not available (e.g., flexibility with direct payments). Other family carers mentioned how services met their relatives' needs through reduced school timetables or remote medical appointments.

"[The Local Authority] sent an email to say that we could use direct payments to buy things that made [relative with learning disability] happy because it wasn't being spent in other ways".

Some negative elements of services include communication breakdown with family carers, as well as reduced access to services so professionals could not conduct health reviews and how this impacted people's inability to be as independent as possible. Another family carer mentioned that they received no financial support, staff or resources at all.

"We've had no money. [The college have] had all the staff and resources and we've had none"

Disruption

The 'disruption' key area encompassed changed routines, shielding, and opportunity for independence. Due to disruptions, family carers said they and their relatives experienced problems including more behaviours that challenge, or inability to carry out regular routines. Similarly, one family carer reported that behaviours that challenge increased once established lockdown routines were disrupted, such as needing to return to school.

"When he came home, he was very angry ... His behaviour has ... well he is calm now because we've had six months of helping him get back again".

Disruptions led to the family carers' relatives with learning disabilities losing activities and skills as they became unavailable during lockdown.

Disruptions to routines during the pandemic and lockdowns were a benefit for some, as tasks that previously upset family carers' relatives were reduced such as sitting in a waiting room. Family carers also reported that some of the disruptions were useful in understanding the support needs of their relatives with learning disabilities going forward, which have continued to be implemented.



“Because of lockdown they [the school] now realise and they've changed his timetable to this 40-minute rotation where he's allowed to leave because they realise that works for him”.

Not needing to engage with services was also reported as beneficial for family carers, as they could spend more time with their relative with learning disabilities and support them to learn skills such as increasing independence.

“Because there were no meetings, there were no professionals, I was just ignoring all paperwork, not opening the post, I could just have a nice time with [relative with learning disability]”.

Summary of findings

Overall, family carers of people with learning disabilities' experiences of the pandemic and lockdowns were mixed, as were their experiences on what worked, and what did not work for them and their relative with learning disabilities.

Key points

- Some discussed how their relationship with their relative changed during the pandemic as a result of the restrictions. We used additional methods (e.g., visual aids) to support interviews with family carers. These additional methods seemed to help family carers reflect on and express their experiences.
- Experiences with support workers also varied; many family carers expressed problems that they experienced with support workers during the pandemic including communication challenges and anxiety surrounding their relative's safety. However, family carers also highlighted positive experiences that they had with support workers during the Covid-19 lockdown.
- Communication problems were also highlighted when family carers spoke about their experiences with services during the pandemic. In

contrast, others spoke about how they received support from services in alternative ways and the long-term benefits that these adaptations could have on their family.

- Unsurprisingly, disruption in some form during the pandemic was raised by every family carer, including a disruption to routine or activities and the impact that had on family carers' relative with learning disabilities. Conversely, family carers also highlighted some positives that came from disruptions in relation to the pandemic, such as not needing to engage with services and being able to spend more time with loved ones.

How can this research be used in the future?

We hope this research is helpful in gaining a better understanding of what is important for families when caring for their relative with a learning disability, and what areas of support are more susceptible to change or problems if unforeseen circumstances arise.

Additionally, future research should focus on adapting policies and guidelines to better reflect a more beneficial system of support and ensure that the problems and disruptions that arose during lockdown are prevented from happening again, and that the best possible care is provided for each family.

Services that support people with a learning disability should use this research, and similar findings, to implement changes to their guidance and practices to ensure that a similar degree of disruption to the lives of people with a learning disability and their families is avoided wherever possible in the future.

This updated guidance should also include information for support workers to limit the amount of burnout that they experience at work⁷, thus allowing them to continue offering the best possible support to people with a learning disability and their families⁸ despite any additional stressors, similar to the pandemic. If care staff are not being supported, it is understandable that the quality of, or capacity for, the support they offer will be reduced.

Finally, it was clear that the needs of family carers are incredibly important, and that these needs must be met in order to ensure that they are able to support their relatives with severe learning disabilities in the best possible way. More support needs to be available for families as a bare minimum,

⁷ Baker, P., Stafford, V., & Hardiman, R. (2019). A cross sectional study of trauma symptomatology among staff working with people with intellectual disabilities who present challenging behaviour. *International Journal of Positive Behaviour Support*, 9(1), 30-37.

⁸ Thomas, C., & Rose, J. (2010). The Relationship between Reciprocity and the Emotional and Behavioural Responses of Staff. *Journal of Applied Research in Intellectual Disabilities*, 23(2), 167-178.
<https://doi.org/10.1111/j.1468-3148.2009.00524.x>

and this support should continue to be available in whatever capacity is possible regardless of any extreme extraneous circumstances.

Next steps

More general research needs to be conducted to implement guidance that aims to reduce future disruptions for individuals with learning disabilities and their families as much as possible, whether this is as broad as a global pandemic or as individual as a school exclusion.

It is clear the lives of each individual involved in this study is entirely unique, and families vary based on factors ranging from age to ability to accessibility of resources. Although there was cross over in the key areas that were mentioned, the experiences of these key areas were exclusive to each individual family carer. Therefore, this research highlights how important it is to consider the individual histories, circumstances, and requirements of each family and then specifically tailor support appropriately and accordingly, and review this over time as individuals get older and circumstances change. More can be put in place to guarantee that individual families access the support they require and deserve. Services that provide support for people with learning disabilities need to ensure that they have policies and guidance in place to prevent the loss of support for so many families of people with learning disabilities.

Recommendations for services and policymakers

Some recommendations that can be made following the findings of this research include:

- Develop a person-centred plan that will include accommodation for emergency situations similar to the pandemic to ensure that there is minimal disruption in accessing support for each individual.
- Ensure that families have a keyworker who will bridge the gap between families and services to minimise disruption in accessing support.
- Allow greater flexibility with personal budgets for supporting an individual with a learning disability.
- Improve communication between family carers and services to reduce confusion and distress in the event of any unexpected changes or removal of services by ensuring regular contact is maintained and offering a variety of methods of communication.
- Improve work surrounding transition both within and between services to minimise disruption and distress caused by the changes.