

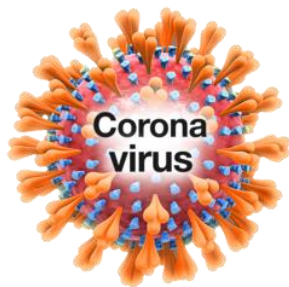
Family Voices:

Families' experience of COVID-19
and what needs to change to make
the future work

September 2020



Easy Read Summary



What this is about

This short paper has been written to share some of the things families have said about what happened to them since March.



It says what they think can be better so more people with learning disabilities and their families can stay well and keep going through Coronavirus.



Learning Disability England wants to make our member voices louder.



We want to make sure their experiences are thought about in how services and policies are made as we live with Coronavirus



We are sharing people with learning disabilities experiences in different ways.

People are making reports, blogs and films themselves or with Self Advocacy groups.



This paper was written to make sure families are thought about too.

Families have told us they feel have been forgotten during Coronavirus



Families hold us what happened when we went into lockdown

Lots of people's paid support stopped overnight.

This meant families had to support people all the time



Some people found this very difficult and it affected their mental health.



Families told us about problems they have had but they also said some things have been good



Problems included things like

- Having less support
- No information on choices or keeping safe



- Extra stress and pressure



Good things included



- People who get very good support made people feel safe
- People feel more in control of their time
- Better communication online sometimes
- Learning what is possible from trying new things



Include family carers as partners in the rebuilding and reshaping of support



Families want support for people with learning disabilities to get better but sometimes their family has been forgotten



Family members want to be included in the work to change how services work.

They can bring solutions as well as explain the support the kinds of support families need.



The four areas families say they need more support now are:



- Returning to supported living
- Services opening again safely



- Using public transport



- Promises that services and support will not be cut.



In the future include family carers when making plans for national emergencies or crisis like Coronavirus

Families told us there is a chance to learn from what has often gone wrong since Coronavirus.



National and local plans can be made with and thinking about the important role family carers play in supporting disabled people.



Disabled people and their families need to be at the centre of government thinking, not an after thought



Families need to be supported to plan for emergencies, so no one is left in crisis



Everyone should have access to phones and the internet.



Social care needs to be well funded and respected. It needs to be flexible to meet people's needs when crises happen

Summary

This short paper has been written to share some of the experience's family carers, who have a relative with learning disabilities, have talked about with the outbreak of COVID-19. It also says what they think can be learnt from their experience.

Learning Disability England wants to make sure the experiences of people with learning disabilities and their families and supporters are thought about in relation to decisions about services and policies in the next year as we live with COVID-19. We are sharing the experiences of people with learning disabilities through reports, blogs and films that people have made themselves or with self-advocacy groups. This paper was written to make sure family carers are also heard.

The main points we have heard are:

- Include family carers as partners in the rebuilding and reshaping of support;
- Include family carers in making plans for a further outbreak of COVID-19 or other national emergencies;
- National and local government, and local services communicating well with families makes a huge difference in helping them to cope and reduces worry;
- Practical and emotional support is needed to help families recover from the trauma and anxieties resulting from COVID-19 including support for people with learning disabilities to regain confidence and independence, and support for families to get plans in place for future emergencies;
- Improve digital inclusion for people with learning disabilities and their family carers to enable them to be socially connected and have access to health and social care services.

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Introduction: family carers with a relative with learning disabilities

There is no one family voice: to cover the breadth of family carers' experiences during COVID-19 would require a book. Families face many diverse challenges and experience a huge variation in support networks and quality of local services. This paper aims to give a flavour of what they have been through with the aims of:

- Family carers' voices being shared and heard
- Their lived experiences being used to inform policy and practice (which failed to happen at times during COVID-19)
- Providing a longer-term, historical picture that can be used to remind people of the value and power of family carers' insight.

The voices come from work carried out by our members and partner organisations as well as others who have carried out surveys and held discussions with families. This paper focuses on family carers whose relative lives in their local community. We know that campaigns like [Rightful Lives](#) and [Right 2 Home](#) and groups like [Bringing Us Together](#) are doing important work to share the impact of Covid-19 on people currently in Assessment and Treatment Units and their families. We encourage you to look at their work.

Family carers are not always parents but may be siblings, grandparents or foster carers. They may have more than one son or daughter with learning disabilities or have other caring responsibilities, such as for

elderly parents. Caring responsibilities often continue when family carers reach their 70s, 80s and 90s. Also, people with learning disabilities sometimes move into a caring role for their elderly parents resulting in an often precarious mutual caring relationship.

It's important to understand that getting things right for people with a learning disability also supports their family carers and getting things right for family carers improves the lives of people with learning disabilities.

Content

This paper describes some of the things we heard from families about what happened to them and their family under the following headings:

- What happened when COVID-19 struck
- What was happening pre-pandemic that caused problems or helped families to cope
- What families said would help them cope with the next phase of COVID-19
- What families said has been positive and needs to be held onto
- What needs to be put in place in case of another major outbreak of COVID-19.

What happened when COVID-19 struck

'I feel a constant guilt that I'm not doing enough for her'

Kate Chate, a parent who lives in Suffolk, was [interviewed by Seb](#) from Ace Anglia, about her experience of lockdown. It takes us back to the initial few months of COVID-19 when life was turned upside down and there were huge amounts of worry and uncertainty. Kate says:

'Everything has changed: I'm at home all the time, all my work is on-line, all my children are at home and all my son's support workers are shielding or have been ill and are now shielding so we are doing all the caring for him.'

Many families found themselves in a similar situation of suddenly finding no support was available and needing to stand-in, often providing 24-hour support to their young person or adult relative with a learning disability. This was in the context of having complete uncertainty of how long this would last when, as Kate says, each week ***'the future felt different'***.

In a blog for Learning Disability England Paula explained how, pre-pandemic, the lives of many family carers already felt like lockdown due to the impact and limitations in their lives when supporting someone at home who finds the world difficult to cope with:

"You look around and see what the Coronavirus pandemic has caused for people's lives everywhere: the job worries, the health worries, the inconvenience, the financial worries, family arguments, the insecurity, the longing for better times, the frustration of bureaucracy and authority....Family Carers live this life day-to-day, every day, Coronavirus or not!"

Also the home education, activities to keep them occupied, feeling trapped in your home, lack of a social life- welcome to our world”

Another account was given by Jane, as part of [Sense’s Forgotten Families campaign](#). Her daughter, Faith, has complex disabilities, which include deaf-blindness and autism and every day has support around the clock:

“The family have done the best we can, but the experience has been incredibly difficult for Faith, and it has been heart-breaking to watch her regress during this period. She is showing signs of anxiety and frustration, rocking back and forth and making loud noises, behaviour that was rare before the lockdown. I feel a constant guilt that I’m not doing enough for her. As a parent and carer you do just get on with it, but I have become increasingly weary and low in spirits as time has gone on.”

Many families talked about how support disappeared overnight, particularly that provided by day centres and short breaks services with little information and support as to how they were to manage. As Philippa commented, ***‘Most of the support went- we had to make up the shortfall’*** and another said, ***‘We just get on with it as no-one else is going to step in’***.

A [survey carried out by Mencap](#) , found that over half of family carers said they had struggled to cope with supporting their loved one during the COVID-19 pandemic with 75% saying the situation has been detrimental to their own mental health, 60% to their relationships and 61% to their physical health.

The fact these figures are not higher would seem to reflect the fact that family carers are used to being resourceful and finding ways to cope.

What was happening pre-pandemic that caused problems or helped family carers to cope

'I felt they couldn't keep each other safe so I had no choice but to ask my son to come back to live with us.'

What caused problems

The reduction in levels of adult social care budgets over a number of years has meant that many systems and services were not robust, and the infrastructure was not in place to make quick changes. Low levels of support and low wages for support staff meant that many services were already struggling to do enough to keep people safe and well. This was one of the main concerns of family carers and improving the status and wages of people working in social care was regularly cited by family carers as the number one lever for change that is needed.

Where services were already stretched, due to factors such as tight levels of funding and difficulties recruiting staff with the necessary skills, families did not have the confidence that their relative would be kept safe from the virus and/or that their mental and physical health would not deteriorate. Jasmine said: *'I felt they couldn't keep each other safe so I had no choice but to ask my son to come back to live with us.'* Jasmine's son enjoys sharing a house with other young men but she felt it was a lot safer for him at the family home rather than *'relying on others with hand hygiene etc when there were inconsistent and low levels of staffing'*.

What helped

Family carers were more able to feel confident about their relative remaining in a supported living or residential service when it was well-managed, staff had good support from their managers and levels of funding for the service or for people's personal budgets was at a reasonable level.

Heather's daughter lives in a small house shared by people who would be described as having a high level of support needs, where everyone has one-to-one support arranged through their personal budget. In this situation it was easier to adapt existing support for people to spend meaningful time indoors, go out for walks and follow preventative hygiene measures. Having well-funded and good quality support has given Heather confidence:

“My daughter’s home used video calling so we could see each other and I could see she was happy and well. It helped me to realise that she doesn’t really need me to be okay. This is reassuring to me as I won’t always be here.”

Heather's story reflects how good support means more than knowing someone is currently safe and well. Family carers play a huge, largely unrecognised role in advocating for their relative, checking on their well-being and monitoring the quality of support they receive. One of their biggest fears is who will do this when they are no longer able to. Heather's experience not only gave her reassurance for the present but also for the longer-term future.

Family carers spoke about the value of local authorities or other organisations having flexible systems and services that could quickly be adapted to provide local support to meet the challenges being faced by families. An example of this was local authorities that were quick to adapt their systems and communicate the changes in their rules about using Direct Payments to pay family members.

What families said would help them cope with the next phase of COVID-19

'This has set us back years'

Philippa's comment ***'We feel we are forgotten'*** reflects many family carers' views that they are being left behind as other parts of society have gradually opened up. Another parent said ***'We're coming out of lockdown into what feels like an unsafe situation'***.

Whilst many families coped during lockdown the best they could, there is increasingly a sense of deep worry about the future. This is both in terms of their relative and themselves getting back to somewhere close to where they were before lockdown and in relation to fear of another outbreak. Some families say it still feels as though they are in lockdown: they remain at home providing 24-hour support to their relative. For those in employment they have the additional stress of trying to work from home or not being able to return to their place of work because of their caring responsibilities.

All these factors have led to a lot of anxiety and trauma being experienced by both people with learning disabilities and their family carers. Family carers say they now need support to move into the next phase ***'at the right pace of change for us'***. The following comment sums up the fact that individualised support to cope with the next phase is needed: ***'There is no bullet-point system out of this mess'***.

Four of the key areas where families say they need more support now are:

- Returning to supported living
- Using public transport
- Services safely reopening
- Reassurance that services and support will not be cut.

Returning to supported living

Many people with learning disabilities moved back to the family home near the start of lockdown. Family carers feel they have been left in limbo about planning with their relative to safely return to their flat or shared house. This is often about sorting out support that will keep the person safe as well as to regain confidence and skills that have been lost.

Using public transport

Many people with learning disabilities listened to the government explaining the dangers of COVID-19 and requests not to use public transport 'unless absolutely necessary'. This has led to high levels of anxiety about going out and about, including the use of buses and trains. Many people with learning disabilities now need to regain confidence to use transport as well as to know the new rules and be able to travel safely.

Jasmine said '***Social distancing is always going to be a problem. My son doesn't have social awareness***'. Other family carers were worried that their relative might sit too close to someone else or may cough and get 'picked on'. They said support to learn new travel skills needs to be offered to help their relative understand the rules both explicit and implicit in order to regain confidence to go out and about.

Services safely re-opening

Families have been left wondering how long they will need to cope before services safely reopen. In many areas there is little information about when day opportunities and short-break services can safely reopen or how it will happen. There is a similar lack of clarity for people who rely on Personal Assistants for their support. Dave, whose 40-year-old son is usually supported by PAs, talked about the confusion:

“The risks for my son are that self-employed PAs and those providing activities will rush back to work in an effort to maintain their ‘clients’ and income. I was advised by a support organisation to check on the government guidelines when I asked about PPE and protocols to keep my son safe.

I can do this, but it made me think about elderly family carers with no access to government websites who might be swayed by a PAs enthusiasm or their relative’s desire for normality. Local authorities providing PPE is not enough when managing a dangerous situation. Families need conversations about a safe return on a personal basis.”

In addition, the closure of generic community services, such as community centres and cafes, libraries and gyms, also affects the daily lives of people with learning disabilities. These places provide social connections and a break from spending the day at home, which is especially important for people with little, or no, funding from Adult Social Care. Often, they are not just places to go but provide crucial, informal support: using a computer in a library or community centre not only provides access to being online for people who cannot afford this, but also practical help to use a computer.

Another aspect that families spoke about are the places where people worked, such as in hospitality, that have not reopened. On top of losing a valued job people have also lost part of their structured week that has often taken a lot of time to set up and sustain.

Reassurance that services and support will not be cut

On top of practical concerns about support, family carers are also very worried that local authorities will make further reductions in funding for delivering the support that their relative has been assessed as needing, and that some of the local services would lose their funding. Mencap's survey found that 72% of family carers who responded are worried that there would be more cuts to come to care packages. Some were already reporting that their relative's day support services had been forced to close for good during lockdown. Family carers need information and reassurance that funding decisions, detrimental to their relative, will not be made.

Family carers have often put enormous amounts of physical and emotional energy into helping their relative to develop interests, learn skills, have a social life, move on from their family home, and go to work. Wyn, has supported her daughter to live in her own flat and have a structured and meaningful week. Her daughter returned to the family home before lockdown as Wyn knew she would be very anxious and unable to cope. She is now concerned as to how her daughter will be able to return without substantial support to regain her skills and confidence. Returning to her flat also depends on regaining confidence to travel alone on public transport as otherwise she would be at home all day.

Reflecting on the impact Wyn said:

“This has set us back years. I can even go as far as to say that the virus has robbed my daughter of her life, all her volunteer jobs and social activities just stopped, her chances of finding other work are minimal, her support hours have become just short phone calls. Fortunately, I am still here to support her, but at 80 I am time limited. All those people out there with a learning disability and little family support are probably left high and dry.”

What families said has been positive and needs to be held onto

“This opened up direct contact with the decision makers and has given the Local Authority a unique and invaluable insight into what families truly need.”

It would be wrong to suggest that lockdown and its aftermath have all been negative for people with learning disabilities and their family carers. Some of the positives which need to be understood and built on are:

- Less pressures and anxiety
- Access to, and use of, digital technology
- Gaining confidence
- New ways of working with statutory services: thinking outside of the box.

Less pressures and anxiety

Some family carers have seen their relative being more relaxed and less anxious because of the removal of stressful situations. Examples of this are not needing to rush in the morning to be ready for transport and not going to environments that can be stressful for some, such as college and day centres. These experiences need to be understood and learnt from when planning future support as services reopen: understanding individual needs can improve the use resources as well as enhancing a person’s well-being.

Access to, and use of, digital technology

During COVID-19 many people with learning disabilities and/or their family carers have learnt digital technology skills, such as using a tablet or video-calling software. The internet has also been useful for people to receive both local and national information and updates. People have been enjoying online activities, such as physical exercise and art, and joining discussions led by self-advocacy groups. [You can view some examples here](#). This highlights the important role digital access can play in building networks and friendships, both very important at the time of COVID-19 and other emergencies.

Patrick and his grandmother, Jenny were in lockdown together and she describes how Patrick has helped her become more used to technology:

“It’s helping us both really. Anything that helps Patrick helps me too.”

There have been a number of initiatives to improve digital access for people with learning disabilities and/or family carers. An example of this is Durham County Carers Support using Carers’ Short Breaks funding to gain the equipment to get online and to access virtual training.

Gaining in confidence

Some people with learning disabilities have talked about their growth in confidence during the crisis which may be through developing skills such as; using technology, getting better at cooking and coping on their own when support workers have not been able to come to their home. People have developed confidence through coping with COVID-19 whilst

remaining in their flat although this has often been with huge amounts of support from their family via phone calls and/or visits.

Katy talked about how she stayed at her flat even though her initial reaction had been to want to go and live at her family home. Katy said

‘to begin with my mum was visiting every day and I was phoning her all the time to ask her things but it’s gradually got a bit less’.

Looking back, Katy said she is very pleased she stayed at her flat as it has built her confidence rather than removing it which she feels would have happened if she had returned to her parents’ house:

‘I like to do things myself. My mum understands the way to support me, she explains and shows me and tells me I can do it. She’s helped me during this to learn to do new things in my flat’.

This knowledge and understanding that Katy describes is often held by family carers and needs to be tapped into and learnt from. Katy’s mother added,

“Katy’s wellbeing was our priority during this time whilst coping with the situation ourselves, and this proved very difficult.”

New ways of working with statutory services: thinking outside of the box

The experience of COVID-19 has led many people to look for alternative ways of doing things, often leading to more co-operative and effective ways of working. There is much to be gained from a different approach to

working with families and realising they have useful knowledge, experience and solutions that benefit practitioners.

Jo Barnicoat's [blog for the Department of Health and Social Care](#) suggests how new ways of working have led to better outcomes for everyone:

“Right at the start of lockdown, we (Oxfordshire Family Support Network) organised Q&A zoom sessions where families could put questions directly to professionals, including the Deputy Director of Adult Social Care and the Special Educational Needs (SEN) Director.

Subjects discussed included COVID related health arrangements, direct payments, transition into adulthood and going back to school/college. This opened up direct contact with the decision makers and has given the Local Authority a unique and invaluable insight into what families truly need.”

Jo also describes workshops run by OxFSN for family carers and social work practitioners to explore how to work better together. Jo describes how Pre-COVID she was ***‘at loggerheads’*** with social services as she supported her son through transition but with the links that were built in the workshops, they have moved on from this:

“Communication became more speedy and efficient. Lock-down appears to have focused minds on all sides to keep talking and connecting. It is essential these lines of communication, established during lockdown, are maintained in the long term.”

What needs to be put in place in case of another major outbreak of COVID-19

“We always have the worry what if we sprain an ankle never mind catch COVID-19”

There is huge fear about the autumn and winter ahead, the potential for a rise in COVID-19 and another lockdown. Family carers have made suggestions about what needs to be put in place in case of another major outbreak.

Clear guidance from Government departments

People with learning disabilities and their family carers felt forgotten about by the Government during the pandemic. When guidance was issued it often didn't take account of the needs of people with learning disabilities and/or autism. This was sometimes followed by significant delays in making the adjustments needed.

Government officials and elected members need to understand the substantial history of family carers contributing to policy and practice and the benefits of consulting with them before producing national guidance. Not to do so leads to people with learning disabilities and their families having their rights ignored.

Adult Social Care being in touch

A survey carried out by Durham County Carers Support showed the importance carers gave to receiving calls from social workers and therapists. In another local authority Annie, a sibling, described the impact when this does not happen:

'Social services have not once been in touch with my 83 old mother who cares for both her daughter and son who have learning disabilities. This has further reduced her faith in social services, and I know she will be very reluctant to engage with them again in the future.'

Whilst a few family carers said they would prefer not to have contact from their local authority, most felt it would be helpful ***“knowing there will be regular well-being checks on the phone with social services”***. This gives family carers, particularly those who are elderly or have limited support networks, the opportunity to talk about difficulties or ask for more help which they may otherwise be reluctant to do. This contact would also provide huge reassurance as they would know that services are still functioning and able to respond when needed. Adult Social Care also need to make sure people with learning disabilities and their family carers know the number to call when they reach the point of needing additional or emergency support.

People with learning disabilities receiving the health care they need

A concern for many family carers has been their relative not receiving the regular health care they need. Health appointments and Annual Health Checks have been cancelled and now need to be arranged so that

underlying health conditions and screening take place before winter and any further crises. NDTi have [developed guidance and listed resources](#) on Annual Health Checks in relation to COVID-19, including information for families. This needs to be promoted in local areas.

In addition, family carers need information about health passports so they can ensure their relative has an up-to-date passport in place in case they need to go to hospital over the winter. During the initial weeks of lockdown, NHSE listened to families' huge concerns should their relative catch COVID-19 and need to go to hospital. They responded to this by working with a number of family carers to create the [COVID-19 Emergency Hospital Passport](#) and similarly, there needs to be publicity about this version of a passport.

Planning for emergencies

The COVID-19 experience has made many family carers very anxious about the future in relation to their own mortality. As Philippa said

'We always have the worry what if we sprain an ankle never mind catch COVID-19'.

Jasmine talked about her ***'What if moment...?'*** and explained

'I had a meltdown for a couple of days worrying what would happen to my son if anything happened to me.'

Together Matters has been talking with families about making emergency plans and what would help:

'There is so much information in our heads that only we know- we need practical and emotional support to get this written down'.

A structure as well as templates for doing this are available on the [Together Matters Website](#) and a variety of support services, such as day opportunities, short break services, social work and carers support groups, need to have these, sometimes difficult, conversations and support families to plan. Local authorities need to be aware that many family carers will now be extremely anxious to make emergency plans as well as plan for the longer-term future.

Access to the internet, smartphones and computers

People with learning disabilities and their family carers need to be one of the priorities for digital access covering equipment, access to wi-fi and training. As one family carer responded in a [Pathways survey](#):

‘No access to the internet and smart phones in 2020 is ridiculous and needs sorting out now’.

Access to the internet at home would have reduced social isolation, helped with practical tasks, such as; shopping and created the ability to have video calls with family and friends as well as health, social care and support practitioners. The lack of internet access may have been a contributing factor to people needing to return to their family home.

Properly funded and flexible Adult Social Care Services

There is also a much bigger discussion that needs to continue about the future of social care, how it is funded and how it delivers support that is person-centred. The experience of COVID-19 has changed the landscape of this and reinforces the need to include family carers in discussions. In many instances, family carers stepped into the gap when social care

services closed or were not able to provide agreed support. It has also highlighted the need for a workforce that is given more respect and better paid.

The final words are from Paula:

“I hope a positive that can come from the situation the world has been in this year is an understanding of how family carers can feel ‘locked down’ from society. Out of love for their family member they drop everything to cope, whether it’s continuous or through periods of crisis, and focus on their loved one’s wellbeing. It can be all consuming, rather like the pandemic.

I also hope people’s experience of limited options, feeling trapped, frustration and loneliness along with worry about their family’s health has shown them some of how carers can feel. I’m hoping just for a little more empathy and support when we campaign for better services and funding.

I’m determined that although the country is going to go through economic difficulties due to the pandemic, people with disabilities and their carers should not face cuts, we have proved our value to society, we deserve respect equal to the NHS.”

About this paper

The ideas in this paper have been brought together from a variety of sources from across England by Christine Towers from [Together Matters](#), an organisation that aims for families to be better supported to plan for emergencies and for the longer-term future.

Many thanks to all the contributors who agreed for their experiences during COVID-19 to be shared. We apologise to anyone who would like to have added their ideas. We were keen to produce something timely for family voices to influence decisions that will be made in the coming weeks and months.

September 2020

