The Challenging Behaviour Foundation
making a difference to the lives of people with severe learning disabilities

Healthcare and Mental Health – New Normal

Learning from the COVID-19 experience to improve practice and outcomes for individuals with severe learning disabilities in a 'New Normal'

The CBF's 'New Normal' survey was created to collect the views of families, professionals, support staff, and others, on how the COVID-19 experience has changed understanding on how services should be delivered and how ideas of 'best practice' have changed. The survey, which ran between September and October 2020, asked a series of open questions on how practices and services have been adapted during the pandemic – to which respondents could provide information on any issue they felt relevant. The aim of the survey was to collect new understandings of 'best practice'; to

The information discussed in this paper represents all survey findings relevant to Healthcare and Mental Health– with 'Datasets' containing direct quotations from survey responses employed to illustrate points made throughout. Also included in the paper is additional material collected at a meeting of our Challenging Behaviour National Strategy Group (CB-NSG). During this meeting, survey findings were discussed alongside research findings of SF-DDARIN 'talking-mats' interviews conducted with family carers, by a range of stakeholders including practitioners, policy specialists, family carers, and others.

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Introduction

The pandemic has had a direct and dreadful impact on health outcomes for many individuals with learning disabilities and autistic people. As of April 9th 2021, 1,525 deaths of individuals with learning disabilities have been notified to the 'learning from death reviews' programme (LeDeR), and this figure may still underestimate the total due to underreporting. Individuals with learning disabilities have also died at a much younger average age than the general population, due to both health factors (such as higher risk of other respiratory conditions, hypertension and obesity) or environmental factors (such as living in residential care wherein infection spread quickly).

There have also been significant indirect health and mental health impacts of the pandemic for a population that already was subject to significant health inequalities and avoidable premature mortality. Access to all healthcare and mental health services have been upended by the pandemic. With hospitals often at capacity, in-person health monitoring and appointments have not been able to take place, and many procedures have been suspended completely. Many people with learning disabilities have endured severe loneliness and isolation caused by lockdowns and reduced contact with family or others, and anxieties have been heightened due to infection fears. The same is true for family members and support workers, who have been caused significant distress due to worries not only for their own health but for the health and wellbeing of those they support.

Responses told us a great deal about the negative impacts of the pandemic on wellbeing, mental health, and healthcare outcomes. However, responses also gave insight into the practices involved in delivering healthcare services and mental health support, and this provides the opportunity to evaluate how these practices should operate in a 'new normal' if they are to serve individuals with learning disabilities and their families effectively.

As this paper will detail, a great deal has changed for individuals with learning disabilities, their families, and relevant organisations when it comes to health and mental health services. It is important to identify what can be learned about the practices employed in these services, and what opportunities exist to implement these lessons to improve outcomes from this disruption. Respondents told us that new forms of delivering healthcare services have brought benefits, as online communications have reduced stress and difficulties when attending appointments, for those who can access them. '**For those who can access them**' is a key qualifier. It has been made clear that there is regional variation in where these services operate effectively online, and that many people do not have access to, or the skills to use, a computer, smartphone, or the internet. It was also noted by respondents and by clinicians during our National Strategy Group discussions that online delivery of healthcare services is often not appropriate for some individuals with learning disabilities, autistic people, or for certain procedures or diagnoses.

Many responses to the survey noted that their own or their family members' mental health and wellbeing was greatly impacted by the pandemic, yet some respondents also told us of the more proactive approach to mental health support that was being generated as a result of the pandemic. We also heard from some families whose relative responded well to lockdown conditions, and were able to identify that previously accessed services had been contributing to anxiety or distress. The purpose of this paper is to collect and share the lessons of the pandemic, and to show where practices can be improved in a 'new normal', reflective of the new understandings of best practice that has been generated in healthcare and mental health. It comes with the caveat that the core principle remains that support and services should be tailored to individual need- what works for one person may not work for another- and that a range of mixed personalised provision is required.

1 - Healthcare

1.1 Delivery of healthcare services

In responses submitted by families, healthcare practitioners and those working in services, there is a large disparity in how respondents reported their ability to access, or provide, healthcare. Some reported that health assessments have not been possible, have been delayed, or carried out only rarely. Health needs outside of COVID-19 were not met, for instance annual health checks suspended, with one practitioner stating that physical health monitoring was not possible at all due to surgeries being overwhelmed. People with learning disabilities faced significant issues in healthcare access prior to the pandemic, including major inequalities in healthcare and diagnostic overshadowing - in which health issues are not identified due to presumptions of an individual's learning disability are already known issues, as is avoidable and premature mortality. These pre-existing inequalities and disadvantages have been further heightened by the pandemic. NHS England data (LeDeR) has shown that individuals with learning disabilities are up to 6.3 times more likely to die from COVID-19[1] than the general population. Alongside aforementioned barriers to online communications, ensuring that health assessments are able to take place in a safe manner is therefore of huge consequence. Responses also highlighted the importance of having support staff trained to recognise key symptoms and to identify where health needs are going unmet.

One family carer told us that getting phone appointments at the GP became much easier than in-person appointments, reducing "*the stress of having to wait long periods in a surgery waiting room*". Another told us that they were unable to access health & mental health support from CAMHS or the learning disabilities team prior to services being provided digitally. This digital option was reportedly an improvement on previous means of access, "*especially for anyone with anxiety or fear of leaving the house*". Practitioners told us during our CB-NSG that they had found Care and

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[1] When adjusted for under-reporting and standardized across age and sex, the rate of COVID-19 deaths for individuals with learning disabilities was estimated to be 692 per 100,000, which is 6.3 times the general population rate as per LeDeR figures.

Treatment Review appointments were less stressful for individuals with learning disabilities when conducted online and in their home. This should be integrated into best practice by continuing to offer the option of online services, potentially in a much more expanded role than existing guidance allows it. This existing guidance for healthcare providers and commissioners presents a limited role for online healthcare. For instance, NICE Guidance 94 (*Care and support of people growing older with learning disabilities*) recommends that commissioners "c*onsider the use of technologies such as telehealth and telecare to complement but not replace the support provided by people face to face*". The pandemic has given reason to reassess this limited role of technologies, and to establish which services could be provided online according to individual circumstances, preference and accessibility given the above benefits, and where healthcare technology for some individuals with learning disabilities may not (yet) be viable.

Of course, there were a range of opinions expressed on the suitability of certain methods of delivering services online – both for physical and mental health support and services – reflective of the diverse backgrounds of individuals who provided responses. This reaffirms the fact that **support given to individuals with learning disabilities and autistic people cannot be 'one-size-fits-all**'. Service design must reflect the fact that individuals with learning disabilities and autistic people (like the rest of the population) don't all prefer or have access to the same style of support.

Existing guidance relating to the provision of support for mental health problems for individuals with learning disabilities (NICE Guidance 54) requires intervention and assessment to take into account communication needs (NG54 1.3.1) and preferred treatment setting (NG54, 1.1.2). Given the ongoing provision of healthcare and mental health services online or by phone, guidance should be amended to explicitly account for an individual's preferred communication and assessment setting, be it virtual, phone, or in-person, as it has been shown that individuals respond differently to the form of appointment delivered according to what they are most comfortable with.

Online healthcare services must be adapted and refined if they are to offer a reliable alternative to in-person assessment for individuals with learning disabilities. While advantageous by increasing accessibility (amongst those who have internet or phone connectivity), during the CB-NSG clinicians reported that there are remaining concerns over how effectively an online assessment will measure the healthcare needs of individuals with learning disabilities. This is because a large degree of non-verbal communication and interaction is lost online, complicating diagnostic processes and often meaning that appointments rely too heavily on the accounts of a family carer or support worker, losing the perspective of the individual with learning disabilities if they are not able to tolerate or communicate using online methods themselves.

As a form of best practice, one practitioner has highlighted the benefits of using 'RAG' (red, amber, green') ratings to assess urgency of need and decide treatment priority accordingly. Alongside online consultations, this development has improved the efficiency of dealing with healthcare concerns. To implement this as best practice in the long run, it should be noted that RAG ratings should make sure that people with learning disabilities or autistic people should not be placed at the 'back of the queue', especially due to expectations of carer's capacity to provide health support.

1.2 COVID-specific healthcare issues

Throughout the early stages of the pandemic, access to fast and reliable COVID-19 testing was of huge concern. Respondents told us that individuals with learning disabilities, their families, and support staff would have benefitted hugely from priority access to testing. The wellbeing of many individuals with learning disabilities and autistic people living away from home (in supported living settings, residential care homes, inpatient units, or elsewhere) - and of their families - was negatively impacted by the curtailing of visiting. COVID-19 symptoms may have been harder to observe in some individuals with severe learning disabilities – meaning that, without appropriate testing in place – individuals who had contracted COVID-19 may have missed out on valuable medical attention during the early phases of infection.

We also heard that adequate testing could have improved COVID-19 safety procedures in residential and social care settings, by targeting isolation to those who need it rather than across all residents, and ensuring that support provided is safe. Proper testing – and testing conducted in a manner appropriate for individuals with learning disabilities – would have also prevented the discharge of COVID-19 positive individuals from Assessment and Treatment Units and hospitals into care settings.

The need for more vigilant Infection Prevention and Control (IPC) which has been brought about as a result of the pandemic has been highlighted as a welcome addition to understandings of best practice. If these IPC measures are continued, it will hopefully contribute to a reduced impact of seasonal infections (such as flu), which also pose a greater risk to individuals with learning disabilities due to the aforementioned comorbidity of learning disability, autism and respiratory conditions and other diagnoses.

1.3 - Dataset

TOPIC	DATA FROM SURVEY
Difficulty accessing healthcare services	Health appointments have been not possible, delayed or carried out virtually a few times. special needs dentistry has completely stopped
	[Difficulty] accessing health care outside of Covid19 e.g. annual wellbeing checks
	Physical health monitoring due to surgeries being overwhelmed. (consultant psychiatrist)
Benefits of new means of accessing	Also it is much easier to get phone appointments at the GP Which has reduced the stress of having to wait for long periods of time in a surgery waiting room.

or delivering healthcare	We have experienced virtual consultations with CAMHS and learning disabilities team have ran courses virtually. This has been very helpful and reduced our waiting times for both services. I think virtual consultations are very beneficial, especially for anyone with anxiety or fear of leaving the house.
	RAG rating patients and supporting them according to their needs. The patient knows when they are going to be contacted and how often. I think moving forward it has given us thought of what works/does not work. We will be better prepared to deal with another peak.
COVID-19 Testing	As my son lives away from home and is in supported living, the most difficult challenge was that we both missed each other terribly. He had terrible tantrums as he was confined at home everyday in his house […] I think there should have been more flexibility in being able to see each other. For example, a test to detect whether anybody has Covid symptoms.
	Adequate testing and results prioritised for care home and carers, testing for people transitioning from hospitals to care homes to avoid self isolation
	Access to testing earlier would have been helpful and it is still a challenge in supported living services.
Infection Prevention and Control	Coronavirus has made the need for vigilant infection control to be 'under the spot light'. People are considering others Safety more now whereas prior to the pandemic this was less evident.
	increased safety due to more rigid infection control measures

2 – Mental Health

2.1 Individuals with learning disabilities

Some families reported improvement to the mental health of their children with learning disabilities as a result of lockdown. Many of these children responded well to the slower pace of life, and – due to no longer attending school – they experienced a low-demand environment which allowed better management of anxiety. As result of this positive experience, one respondent has decided to home-school their child. This highlights the way in which the pandemic has challenged our assumptions of which services work best for individuals with learning disabilities, showing that established/familiar services may in fact act as a negative stimulus for an individual's mental health issues - it is only once that stimulus is removed that it is identified as a causal factor for ongoing anxieties. As is detailed further in our paper 'New Normal – Social care', we recommend the continuous and thorough evaluation of whether services on offer are truly creating good outcomes for individuals with learning disabilities.

Families were, however, twice as likely to report negative impacts to the mental health and well-being of their relative with learning disabilities than positive. For many of those whose children were at home, the pandemic and the loss of access to preferred activities or familiar services created high levels of anxiety. For those living away from home, in supported living, residential care, Assessment and Treatment Units (ATUs) and elsewhere, the fact that visits were either suspended or much changed (in particular lacking physical contact) entailed emotional challenges, and for some an increase in challenging behaviour. This was not necessarily an unavoidable consequence of the pandemic, and this report has mentioned already the difference that adequate access to testing could have made.

We also heard that some service staff and support workers may lack a full awareness about the mental health needs of those they support, and as such are able to offer a reduced level of targeted and proactive intervention. Existing guidance on health and support staff training on mental health problems amongst individuals with learning disabilities and/or autistic people[2] should be more rigorously implemented, and expanded to reflect the level of co-occurrence between mental health problems and challenging behaviour, and the appreciation that early intervention may prevent this.

This was not universal – and in fact we heard from others who had found staff and management taking a more proactive approach to mental health and wellbeing work, especially in education where such mental health work "*didn't happen unless children showed signs that they required support. Now it is more about preventing these issues*". Going forward, the continued engagement with mental health and wellbeing work on a proactive or preventative basis is recommended as best practice.

2.2 Family carers

The removal of established activities services for individuals with learning disabilities and autistic people, alongside the national restrictions and necessary shielding for some, created full-time caring and education responsibilities for families. With no respite services available (for some), for many family carers well-being worsened and exhaustion increased. This has meant that families have often found themselves having full-time caring responsibilities – and significantly, this has not been matched with an increase in financial support. This is detailed further in our paper New Normal – Social Care, and quantitative studies of carer's mental health and wellbeing have explored the impact the pandemic has had on family carers mentally and emotionally. In particular, Swansea University found that family carers for children and adults with learning disabilities reported rates of mental health problems under lockdown that are up to 10 times higher than parents without those caring responsibilities.

As per NICE guidance (ng54, ng150), carers' rights to receive support (including Carers' breaks, community support, financial support and more) for their own needs is recognised, as too is the fact that many carers "struggle to maintain their own wellbeing and overlook their own needs because of their caring responsibilities"

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[2] NICE guidance 54 instructs that all health, social care and education services should train all staff who may come into contact with people with learning disabilities should be expected to be aware of the increased risk of mental health problems amongst individuals with learning disabilities, that these may develop and present differently, the reasons they may arise, and that mental health problems are commonly overlooked in people with learning disabilities.

(NG150, p49). The recognition of this issue, along with the identification of the risk posed to carers' wellbeing, makes the blanket suspension of services and insufficiency of financial support offered to replace them even more questionable.

Furthermore, after discussing carer's mental health needs in a workshop at our Challenging Behaviour National Strategy Group, the issue arose that there has been a great variation in how mental health outcomes have been impacted between members of the same household (for instance, a child with learning disabilities may have experienced decreased anxiety due to the low-demand lockdown environment, while their siblings found that having their loved one at home 24/7 lead to increased care responsibilities and decreased parental support for their own needs). This means that, without an understanding on how mental health outcomes can diverge between individuals in the same environment, commissioners may have a 'blinkered vision' of what support is needed to maintain the wellbeing of the entire household. For some families, 'respite services' are ideal, however for others, targeted support (including befriending, family networks, upskilling, counselling) would be much better suited to ensuring that they can maintain their wellbeing and -where appropriate – continue to offer high-quality support for their loved one. Discussions at the CB-NSG concluded that, as we emerge from the pandemic, it is important that we better understand that families and wider support networks have their own mental health needs, often specific to that person or their circumstance. Appropriate mental health support for these families means employing individualised means of support, creatively applied, and person-centred, rather than only an offer of the respite model of 'nights off'.

2.3 Accessing support from mental health services

Mental health issues faced by individuals with learning disabilities, autistic people and their families during the pandemic were exacerbated by the difficulty many experienced when trying to access support or appointments from CAMHS. There was a large discrepancy in how respondents reported this – as outlined above, many found the online format made accessing support much easier. Others meanwhile, found that appointments with CAMHS stopped, and responses from those working in services found that offering emotional support to families over the telephone was significantly less effective than it had been in-person. Practitioners told us during our CB-NSG that they have found it difficult to refer patients to mental health services for anything other than emergencies.

2.4 Improved outcomes or support offers

A large number of those working in the learning disability field found that changed working habits provided mental health benefits – brought about through spending less time travelling between meetings, appointments, or commuting, and spending more time attending to well-being (through mindfulness, exercise, prayer, engaging with nature, and generally reduced stress).

Furthermore, in responding to the issues of anxiety, distress, isolation and more which were heightened during the pandemic and lockdown, many workplaces and services appear to have developed an increased awareness of the mental health needs of those they interact with, and some have responded accordingly. This has included engaging people with learning disabilities and their families or staff in wellbeing courses, co-developing well-being plans with these individuals, and allocating time and resources to mental health work on a preventative basis, rather than reactively or only when individuals showed signs of need.

However, as mentioned, family carers well being and mental health deteriorated during the pandemic, and in responding to the CBF New Normal survey they were far more likely to report exhaustion, anxiety and distress compared to professionals in the field. It is important to note that many mental health and wellbeing support methods discussed in responses were reported regarding individuals with learning disabilities or for professionals working in the field – we heard far less about support being provided to family carers or support staff. We welcome the increased focus on mental health and wellbeing generated due to the challenging emotional and mental circumstances of the past year, and the support being delivered which possibly wasn't available prior to the pandemic. However, it is essential that this is universal, and that family carers, support staff, and those individuals with learning disabilities who do not have online access are not 'left behind'.

2.5 - Dataset

TOPIC	DATA FROM SURVEY
Low demand-environment beneficial for some individuals with learning disabilities	Some of the people we support have enjoyed a slower pace and being around less people. We have all appreciated the beauty of our natural environments more
	My son finds any demands on him creates anxiety and he self injures to avoid less preferred activities. School proves difficult despite minimal demands being placed on him. At home we meet all his preferred needs and activities to help him manage his anxiety. This is exhausting for us as he needs little sleep and enjoys being driven for hours to self regulate. Having no school and clear roads with fewer people about made our lives and his less stressful.
	During lockdown my daughter was in a great mood - happy, calm and accepting of the situation, presumably because each day was predictable with few sources of anxiety. Of course, we could not see her at that time.
Increased anxiety and challenging behaviour (due to infection worries, loss of preferred activities/routines, distress)	His safe routines are what keeps him stable and lockdown completely dismantled theses safe routines. This was very tense and challenging for all of us who support him.
	My child's anxiety has worsened. She refused to leave the house for the majority of lockdown. She became extremely distress when anyone went outdoors. Meltdowns increased. She withdrew from family life feeling her bedroom was the only safe place for her. Her appetite decreased. She refused to participate in school work, she was worried her parents would die. This is a shortened version.
	This period has made them very anxious and resentful of not being able to see family when they wanted too.
	Trying to cope and manage working and caring full time and maintaining my mental health

Impact on the mental health of family carers, support workers, and professionals	As the employer of his team of ten support workers, I had to furlough a worker who was advised by the NHS to shield, […]. The worker concerned was, and is still, extremely frightened by the danger she feels she in due to Covid-19. She has since resigned. She was an experienced long term worker for us and is much missed. Recruiting is problematic of course and training is also difficult given restrictions and the risk to myself who am now 74 years old.
	I have enjoyed not having to drive miles from school to school and back to clinic for appointments, which have been done over the phone. I now down tools at 5pm and am able to go for a walk for an hour before my evening meal, instead of being stuck in a car for an hour, improving my health dramatically.
Importance of awareness/training surrounding mental health needs	lockdown highlighted for us the extent of her anxiety and her ability to manage it when well and hence the need to pay more attention to the specific support she may need when not in a good place.
	A better understanding from authorities about the very real dangers to mental health overriding the dangers of Covid to my daughter and others in her position.
Increased investment in mental health support	Recently a CLDT nurse has become involved with my daughter to assist in managing her anxiety.
	More work carried out with all children regarding mental health. Time was not allocated previously to this. It didn't happen unless children showed signs that they required support. Now it is more about preventing these issues. Time allocated in the timetable. We have had support from trail blazers on resources and the RISE website is great
	We have implemented short Wellbeing courses for people with LD and their families or staff - 2 sessions to look at anxiety and well being - resulting in people developing their own Feeling Good plan

Conclusions

This report has highlighted some key areas for consideration for those designing and delivering health and mental health services going forward, these include:

- **The potential benefits of offering the *option* of online physical and health services for people with learning disabilities**. However, when offering online services, consideration must be given to the specific communication, behavioural, and health needs of individuals with learning disabilities must be taken into account to ensure that they are not excluded from accessing services they are entitled to. This must also not replace the offer of in-person appointments, which are the most effective route for accessing healthcare for many individuals with learning disabilities. In addition, inequalities in digital accessibility must be addressed, to ensure that *all families* can benefit from these. For more details on how individuals with learning disabilities and their families reported their experiences of online communications, please see our paper 'New Normal – Communications and Education'.

- **Provision of proactive mental health support to family carers and support staff .** This is especially important in light of the toll that the pandemic, successive lockdowns, and withdrawal of services had on individuals with learning disabilities, families, and support staff
- **Ensuring services are person centred**. Some services have been withdrawn for people with learning disabilities due to the constraints of the pandemic and the impact of this has highlighted the value of these services for people with learning disabilities. Some people with learning disabilities have really struggled without these services and for others, respondents found that individuals with learning disabilities benefitted from no longer attending services or settings which were contributing to diminished wellbeing. More details on which are available in New Normal – Social Care.