

Lessons learnt from the COVID -19 Pandemic: Good Practice

Embedding learning and good practice into the 'New Normal' to ensure positive outcomes for people with learning disabilities

Background

Significant inequalities and accessibility issues existed for children, young people and adults with learning disabilities, autistic people and their families prior to the pandemic, with individuals who display behaviour that challenges being additionally disadvantaged and excluded from many services. It goes without saying that the pandemic has increased the challenges faced by individuals with learning disabilities, their families and those working in services, care and other relevant fields. Alongside the tragic rate of mortality for individuals with learning disabilities, their support, health, and education needs have often gone unmet, disabled people have been overlooked in government policy and guidance, and in some instances their human rights have been undermined. Their families too have struggled, with an increased care load, reduced support from local authorities and many other challenges, while those working in the learning disability field have had to deal with the disruption to normal methods of delivering support and services.

The pandemic has been incredibly detrimental to the wellbeing and welfare of most individuals with learning disabilities and their families. However, amidst these challenges and disruptions, there is the opportunity to re-evaluate how well the established practices and services *actually* worked for individuals with learning disabilities and their families prior to the pandemic. People have had to respond to the demands of the pandemic by adapting; implementing new working norms or new methods of delivering support for individuals with learning disabilities or their families. There is an opportunity to record how these changes have impacted on outcomes for people with learning disabilities and their families. It is important that lessons from the pandemic are built on, so that the most effective means of supporting individuals with learning disabilities are embedded as best practice in the long run. For this reason, the CBF was commissioned to conduct a survey to collect and share instances of 'good practice' – the innovations, adaptations or new methods of working generated during the pandemic, relevant to provision of support, healthcare, education and more for individuals with learning disabilities.

Between 9th September and the 1st October 2020, the CBF's 'New Normal' survey was open for responses, collecting information from a range of respondents about their experiences of the pandemic. Of the completed responses, 43% were from family carers, another 43% worked in the learning disability field, 9% worked in a related field, and the remaining 5% were some combination of the above (all figures are to the

nearest whole number). The findings of the survey were considered alongside concurrent work undertaken by researchers from [SF-DDARIN](#), who conducted a series of interviews using ‘word-map’ interview methods with family carers to discuss how they have been impacted by the pandemic. Together, findings were discussed at our [Challenging Behaviour National Strategy Group](#) meeting in November 2020, where specific actions were discussed to address some of the key issues raised.

The findings from this work have informed a range of recommendations regarding:

- **where existing practices and guidelines are no longer working** – or perhaps were already not working - for people with learning disabilities and autistic people.
- **specific ideas of good practice** which should be embedded into a ‘New Normal’ to improve outcomes for individuals with learning disabilities and their families.

Reports on sector-specific findings and policy recommendations for [healthcare](#), [social care](#), [communications and education](#) have been published, and in these reports you can find categorised data tables of information submitted by respondents. Meanwhile, **this report will summarise the specific ideas of good practice** which have emerged which should be embedded into a ‘New Normal’ to improve outcomes for individuals with learning disabilities and their families. It is useful to read the supporting reports alongside this one, as – due to this paper’s focus on good practice experience – it presents an optimistic selection of information collected which is not representative of survey findings as a whole.

Healthcare

Online Healthcare and mental health service appointments should be continued to be offered online as an option if appropriate alongside in-person appointments. Many have found that virtual/phone consultations have been beneficial for their relatives with learning disabilities – no longer “*having to wait for long periods of time in a surgery waiting room*”, and having obvious benefits “*especially for anyone with anxiety or fear of leaving the house*”. This is not to say that online appointments should replace in-person appointments – we heard from some families that online appointments were not suitable to their relative’s communication needs, from some practitioners that certain appointments (specifically assessments, behavioural observation and health monitoring) could not be effectively conducted online, and that many cannot access online healthcare services. Please read more on this in [‘New Normal – Healthcare and Mental Health’](#)

The pandemic conditions demanded improved infection prevention and control measures which will help prevent seasonal and other infections used in residential services, day services, or education settings. These practices include teaching methods for regular hand washing for individuals with learning disabilities and compulsory hand washing for visitors, and the improved monitoring of key

symptoms (such as temperature and respiration), which (if carried forward) will help to prevent seasonal and other infections.

Mental Health

Proactively offering mental health support to people with learning disabilities, supporting staff and families

Due to the increased mental health support needs felt by many during the pandemic, some services (in education and children's social care) began to offer mental health support proactively to those they support, rather than only when signs of severe need began to emerge. This has been effective and reduced the severity of issues when they do arise.

Similar measures have also been effective for supporting staff during the pandemic, and some hope to implement this mental health support as good practice moving forward, "*focussing more and keeping mental health at the forefront of our thinking and understanding*".

Social care

Employing consistent and devoted teams of support staff for individuals or groups in residential care as much as possible, rather than allocating support staff randomly or based on availability. Many services initially implemented devoted staffing simply to reduce the spread of infection but have found this reduces the anxiety of staff and those they support, whilst also improving relationships.

Offering a range of purposeful activities as appropriate to the situation. With the established activities or facilities closed, we heard that support staff responded creatively to the need for new ideas or activities. While some options were unavailable due to lockdowns, staff found replacement activities (such as replacing regular trips of rebound activities by purchasing a trampoline), identifying COVID-19 safe ways of maintaining activities (such as meeting families in outdoor public areas), or used inventive ways to explain COVID-19 regulations to individuals who may not have immediately understood the reasons for activity closures (such as visiting all of the closed facilities to explain they cannot use them). Many individuals with learning disabilities missed these activities or their families greatly, however the creativity support staff showed went some way to alleviating this challenge. Given the detrimental effect that the suspension of visitation had on the wellbeing of many individuals with learning disabilities and autistic people living in residential settings (covered more under mental health in ['New Normal – Healthcare and Mental Health'](#)), it is regrettable that this same flexibility was not permitted to prioritise visitation, ensuring it could go ahead in the safest possible manner.

We also heard from support staff who reported being 'allowed' to **be more creative than they are usually due to the urgency required to meet needs in whatever way possible**. Staff should be empowered to offer innovative means of support

going forward, with upskilling to ensure that regulations are upheld without being overly restrictive.

Service providers and organisations adjacent to service provision should be willing to **question whether the services on offer are really preferred by those who use them**. With the established norms of services and activities removed, we have heard that some individuals with learning disabilities are “*voting with their feet not to return to that “normal” now they have been supported at home and other opportunities, ventures and experiencing have been made available to them*”. This is not, of course, to endorse any reduction in provision of services – as we know how detrimental the loss of services (and day services in particular) was for many. Instead, this should encourage those working in services to engage in constant re-evaluation to ensure that services, activities, and opportunities provided are *actually* preferred by those accessing them, or whether their service design could be more person-centred.

For more information on how Social Care adapted to meet the needs created by the pandemic, read [‘New Normal – Social care’](#)

Families

Some instances of improved relationships between families and professionals.

Although many families have not found that professional and family relationships have improved during the pandemic, there have been some important examples of good practice to develop and build upon. In order to better coordinate education and the provision of online services at home, some families and some of those working in these fields reported that there has been **more regular contact**, and the two groups – families and professionals – have enjoyed **improved relationships**. In terms of good practice, one parent told us that arrangements were made to deliver half of the education sessions at home, and the other half at a different placement. This reduced traveling times and **improved coordination and planning between parents and teachers**.

Other examples of good practice relating to these relationships include arranging regular night-stays for an individual with learning disabilities whose family decided they wanted him at home during the pandemic, but could not manage full time care, and the employment **of digital support planning and daily records** to allow families greater involvement in support and care, including reviewing outcomes and support strategies.

Some families also reported an improved ability on the part of the general public to **sympathise with the day-to-day restrictions and challenges faced by individuals with learning disabilities and their families**: “*I think the rest of the population have maybe experienced the restrictions which families and people who have disabilities experience on a day to day basis.*” From this, various instances of good practice were implemented: sunflower lanyards and priority shopping slots, support from local ‘coronavirus hubs’ and volunteers, clear panelled masks and

'exemption from wearing face-mask' cards are some of the instances in which this greater social understanding has been reflected in practice. These measures were not always perfectly executed (shopping slots in particular have been practically limited), but they represent the newfound solidarity many experienced during the pandemic.

Communication

Use of online communications has brought specific benefits for individuals with learning disabilities, their families, and those working in certain related fields for those with access to the internet. While respondents did not universally report that these online communications have been beneficial, the reported benefits included:

- For a provider of supported living, conducting meetings online enabled tenants to invite managers, family or others to meetings for support.
- For *some* individuals with learning disabilities accessing online healthcare appointments have reduced anxiety around waiting or leaving the house.
- In SEND education, online lessons have enabled learners to stay better in touch with their peers, and many individuals with learning disabilities have learnt to use new technologies well *"Some great success getting learners with learning disabilities onto Skype to allow them to join into group chats, see their course friends and share emotions and experiences through the pandemic. More of this should be encouraged I feel."*
- For professionals working in the field (including those in support organisations, practitioners, government organisations, and others), online communications have reduced time and resources spent travelling, improved healthcare and mental health by increasing free time, and improved relationships by enabling easier communications between those separated by distance.
- It has improved co-ordination between services, including the sharing of critical information, therefore reportedly improving quality of care being delivered.

The adoption of new forms of communication – in particular video production to provide information – has made resources more accessible for some people *"We have learnt that people find this medium much easier to relate to"*. People should be willing to investigate whether their established forms of communication are the most effective.

Improving digital inclusion Respondents also informed us of the benefits of efforts made to involve people in online communications who had previously not been able to access these spaces. - including the purchasing of devices and training of staff. It is essential to ensure that **digital spaces are made accessible to all** and that **communication needs or preferences are met for people who cannot or choose not to use digital communications**. This is particularly important as we come to decide what role these digital communications will play in work, social, and

service fields as we eventually emerge from the pandemic. There is a need to ensure that the “digital divide” does not widen.

The use of clear-panelled masks or visors should be adopted as best-practice as widely as possible, to mitigate the barriers to communication posed by mask-wearing for those who lip-read or rely on facial expressions & non verbal cues for communication.

Education

Opportunity for home schooling, potentially to be combined with attending school as appropriate. Some people found that educating their relative with learning disabilities at home during the pandemic lead to a lower stress environment with fewer causes of anxieties. Moving forward, some have decided to home school their child full-time. For others, a mix of home education and bespoke classes has been preferable – *“it’s much better to have one education session at home as it means that one can liaise well with the education team and see some of the work being done first hand and this gives us ideas of activities that can be done at other times of the week”*. Again, this is not a universal finding - it does not mean that online lessons or homeschooling are appropriate for all individuals. Nor does it mean that school-based education should no longer be offered, or that the benefits of social experience and peer interaction are in any way insignificant.

Open minded approach to teaching Some educational professionals have stated that expectations of how well learners could adapt to online lessons have been exceeded, and a lesson has been learned in *“managements assumptions and expectations of progression with little or no interest in an individual’s aspirations”*. Moving forward, education services should endeavour to teach skills truly based in individuals’ aspirations rather than based in presumed incapacity.

Creation of a less overwhelming educational environment. Measures such as scheduling changes to reduce numbers of children in corridors or lunch halls at any one time, the adoption of year group bubbles, and social distancing measures had been implemented to reduce contact and prevent infection. However, those working in education have also found that this meant the environment has been more controlled, quieter, and less busy which has been beneficial to some children who have found the environment less overwhelming.

For more on the changes to practice and policy which might emerge from the pandemic for our communications and those working in education, see our report [‘New Normal – Communication and Education’](#)

Conclusions

This report has highlighted some of the ways in which individuals and organisations have implemented creative and effective **new forms of good practice**, whereby adaptations and changes have been made according to individual need. The successes of an outcome-oriented approach and the focus on meeting needs should

encourage those working in support and services to regularly review and adapt practices employed.

Some of the ideas discussed in this paper are simple to implement, while some will require more long-term planning. They all, however, should give cause to re-evaluate how practices are organised, and should prompt ongoing engagement with individuals with learning disabilities and their families to evaluate whether established practices and working norms actually produce good outcomes for people with learning disabilities.

The findings of our 'New Normal' survey - along with findings from the [SF-DDARIN](#) interviews with family carers - were discussed at the Challenging Behaviour National Strategy Group in October 2020. From these discussions, and employing the more general findings of the survey, we have produced supplementary reports on specific policy areas. These three reports – which cover [Social Care](#), [Healthcare & Mental Health](#), and [Education & Communications](#) – have been published on the CBF website, and contain select data provided by respondents. These papers include more granular policy and practice recommendations based on information collected from the survey, and the in-depth discussions held by CBNSG members. This will be published alongside the findings of SF-DDARIN interviews held with family carers, which have explored in detail families' experiences of the pandemic.

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