

New Normal - Social Care

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 practices and services – to which respondents could provide information on any issue they felt relevant.

The information discussed in this paper represents all survey findings relevant to Social Care – 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.

Table of Contents

Introduction	2
1 - Workforce	3
Family and Staff anxiety, PPE & Guidance	3
1.2 - Employment & recruitment	3
1.3 – Best practice	3
1.4 - Dataset.....	4
2 - Service Provision	5
2.1 – Routines and Activities	5
2.2 – Best Practice	6
2.3 - Dataset.....	6
3 - Housing	7
3.1 - Visiting relatives	7
3.2 – Guidance & Testing	7
3.3 – Housing choice	8
3.4 - Dataset.....	8
4 - Conclusions	10

Introduction

Due to the demands of the pandemic, the way that social care services are accessed or delivered needed to be changed significantly. Many services – including respite services and some day services – [completely stopped](#). Aspects of residential social care which posed an infection risk, such as visitation or social activities, were also disrupted. Meanwhile other components of social care – particularly the way support staff deliver support – had to be [creatively adapted](#) in order to continue safely. Some support staff struggled with [pandemic-related anxiety, stress](#), or had to shield themselves. Meanwhile family carers found themselves with a drastically increased [care responsibilities and financial strain](#).

This disruption, while challenging (and, in [some instances, preventable](#)), offers the opportunity to re-evaluate how well care and services were actually working for individuals with learning disabilities and/or autistic people prior to the pandemic. As a result of this re-evaluation, we heard from multiple families that they have since decided that the care their loved one was receiving [was not actually preferred by them](#), and the disruption of the pandemic helped them to realise that their ‘normal’ care and support had contributed to poor wellbeing. We heard from those working in services that, once different activities and opportunities were presented to their residents or to those to whom they deliver support, those individuals decided that the new, different opportunities are [better suited to them](#). Responses also told us the impact of losing certain aspects of social care which were suspended due to the pandemic - including visitation (in particular, physical contact such as hugging) – once taken away were difficult to cope without. This has had a great impact on the wellbeing of those who use these services, which is explored in greater detail in the ‘Mental Health’ section of our [New Normal - Healthcare and Mental Health paper](#).

As well as dealing with direct instances of best practice, respondents also told us a great deal about the *context* of their interaction with social care – that many of the issues raised during the pandemic were not necessarily unique to pandemic conditions, and rather that existing issues have [been exacerbated by it](#). These contextual issues involve financial, regulatory, and relationship-based problems between families, Local Authorities, support providers and governmental bodies.

It is important to learn from the experience of how social care has been impacted by the pandemic – either in terms of what is new, or in terms of what was already not working prior to the pandemic and lockdowns. This paper deals with these topics in three parts – focussing on Workforce, Service Provision, and Housing in that order. For respondent data on statements made please consult the data table which follows each section.

1 - Workforce

Family and Staff anxiety, PPE & Guidance

Families and support staff have been at the forefront of promoting safety for individuals with learning disabilities throughout the pandemic, but we heard from many (family carers, employers, and those working in services) that families and staff have struggled to maintain their own well-being, and feel that insufficient attention has been given to their safety. Families and support staff have not been appropriately supported with the provision of testing, PPE and clear guidance around the restrictions and regulations. Many support staff have felt anxious during the pandemic – with working from home obviously not being feasible for most in this field. This has led to increased stress, with some resigning their posts due to the anxiety over infection risk. This anxiety has been compounded by poor provision of PPE, a lack of clear guidance and specific support/advice for support staff, as well as a reported lack of clear leadership within service organisations.

The lack of direct and clear guidance created specifically for the care industry was a frequently raised issue. While some organisations responded quickly and created their own guidance for staff in lieu of government direction, we received some concerning comments of social workers and/or support staff acting against early COVID-19 guidelines due to a lack of direct specification on how the care sector was to change under pandemic conditions.

1.2 - Employment & recruitment

Individuals who directly hire support staff for their relative with learning disabilities have struggled to recruit replacement staff for those shielding or who had resigned, and many respondents noted that the increased care needs of their relative (due to the closure of day services and respite services, and support staff isolating) was not reflected by an increase in Direct Payments from Local Authorities. Families were undertaking full-time care for their loved one, without any correlating increase in funding. Furthermore, we heard that when one family requested increased support from their Local Authority, an offer was only made in the form of a residential placement – an option which had already been deemed inappropriate for their relative – this is discussed further in the following section ‘Housing’.

This issue was discussed during a workshop of our Challenging Behaviour National Strategy group, wherein one family carer said further that when their personal budgets *were* increased so that they could directly hire support staff or personal assistants, there was little information or support in place to assist them in the process of hiring, meaning that families have found themselves as both carers and employers with little to no support in these roles.

1.3 – Best practice

However, some forms of good practice have emerged due to the above challenges. Due to the risk of infection between staff and those they support, many services changed their methods of staff allocation – rather than allocating staff based on

availability, services constructed ‘core teams’ of dedicated staff allocated to specific individuals/groups, to reduce the risk of spreading infection widely. We have heard from both families and services that this has been beneficial – reducing anxiety of staff and those they support, and fostering stronger relations both within the team and between staff and those they support.

Support staff have also responded creatively to the limited options for activities, developing virtual activities where appropriate, and replacing preferred activities with COVID-safe ones. One specific example came from a residential placement, where a support worker purchased a trampoline to provide activity and exercise while rebound activity facilities were closed. Of course, a trampoline is not a suitable long-term replacement for rebound activities – much needed services and therapies should not be restricted, and given their importance it is regrettable that these services were not supported to remain open safely - but the creativity shown by support staff made a great difference to many respondents. Support staff should be empowered with the ability to act creatively to ensure that support needs are met in inventive and practical ways. The professionalisation of Social Care is central to equipping support staff to empower those they support, and will enable those working in these services to carry forward the creativity they have shown during the pandemic - without undermining the necessary safeguarding and regulations which inform best practice in support work.

For professionals working in the learning disability sector, who are more likely to have been working from home, creative instances of good practice relate mainly to maintaining relationships, overcoming isolation, and attending to well-being. This involves regular network meetings, socially-distanced outdoor ‘walk and talk’ meetings, and developing online options for regular communications.

1.4 - Dataset

THEME	DATA FROM SURVEY
Staff infection risk and mental health	There were a couple of staff who did not want to come to work because of their anxiety around Covid and obviously some staff who could not work due to shielding.
	As the employer of his team of ten support workers, I had to furlough a worker who was advised by the NHS to shield, this left our small team considerably short staffed at a time when their stress levels were peaking high, (not to mention mine) this furlough process has proved stressful and time consuming. The worker concerned was, and is still, extremely frightened by the danger she feels she in due to Covid-19. She has since resigned.
	Trying to deliver his support ourselves during lockdown in order to minimise the opportunity for him or his staff team to become infected with the COVID virus
Poor government guidance and provision of PPE/Testing for the social care sector	There was limited support or advice available from local authorities at the start of the pandemic. Most organisations I know had already developed their own plans and protocols before any official guidance was given out. Access to testing earlier would have been helpful and it is still a challenge in supported living services.

	<p>Social worker (SW) at the beginning of the pandemic with isolation restrictions from 23.03.2020 wanted to go against public health advice and continue with an outing that week. As a carer I had to repeatedly say I would only follow public health advice and it was not the time for my son to visit another household in another town.</p> <p>Clearer more accessible guidance re PPE, Quicker guidance on restrictions for care homes/day services/supported living homes, Free and accessible PPE from the start, Adequate testing and results prioritised for care home and carers [would have been beneficial]</p>
Under-provision of financial support to families by Local Authorities	<p>the LA could have provided funding for full time support instead of just 40 hours, which means that my husband and I are unpaid carers for 168 hours a week.</p> <p>Not enough Carer support From Local Authority who has been refusing to provide more than 40 hours a week for someone who needs 2:1 support during day and 1:1 support at night. Instead the LA is funding a place in a care home for the person to return to for the last 6 months even though the LD adult is absolutely adamant that they don't want to go back there and an independent social worker has written to court saying that it is in LD's best interest to reside at their family home.</p>
Benefits of core/dedicated staffing	<p>Less random allocation of carers over the pandemic so far has had benefit for my son lowering his anxiety levels</p> <p>Core teams have been beneficial developing a stronger team and therefore offering better support.</p>
Support staff creativity	<p>Staff have been incredibly creative through necessity</p> <p>As my sons staff all had ppe and he had the space to roam on site where he lives this has not been much of a problem, but got new outdoor trampoline, which has been great, because swimming pool closed and rebound activities not taken place, so having outdoor trampoline has been fantastic for my son and his housemates</p>

2 - Service Provision

2.1 – Routines and Activities

The sudden withdrawal of established routines and preferred activities created significant challenges in addition to the other pandemic challenges experienced by the whole population, and led many individuals with learning disabilities and autistic people to experience greater anxiety, increased challenging behaviour, and reduced feelings of security. The closure of day services in particular was one of the most discussed issues for families with relatives with learning disabilities. One major discrepancy between responses data was that these closures were not universal, and those families which still had access to day services credit them as a lifeline during the pandemic. Moving forward, more information needs to be shared between these services to identify why those that opened could open, whether it is safe, and whether others could follow their example. Whether families have access to services to which they are entitled should not be left to a 'postcode lottery'.

Furthermore, a respondent from an organisation working in supported living and community support has told us that individuals they support have 'voted with their

feet' not to return to day services as "normal". With individuals having been supported at home, with different opportunities and experiences having been made available (often via the creativity of support staff), many are reluctant to return to previous arrangements of services and activities. The loss of services was difficult for many, but the COVID-19 experience has reaffirmed the need for services offered to be truly person-centred. It is only once new opportunities have been offered to individuals with learning disabilities that many of those working in services have recognised that previously offered services were not the most suitable. Multiple respondents told us that the pandemic has highlighted how service providers (in education, residential care and social care) may have been limited by their assumptions on what may work for – and what may be preferred by – individuals with learning disabilities and/or autistic people. As best practice, services should be willing (and resourced) to make their support truly person-centred and implement the Care Act as intended, to ensure that supported individuals 'live a life of their choosing' rather than one chosen by commissioners or Adult Social Care.

2.2 – Best Practice

This issue of person-centred services was discussed in depth at our CB-NSG, and discussions focussed on how to fully implement this person-centredness as best practice within social care. Practitioners told us that often the creation of personalised care and support planning can simply be a 'box ticking' or 'copy and paste' task, with time constraints and insufficient checks leaving actual person-centredness neglected. Furthermore, it was recommended that Social Care's 'push' culture (i.e. once an individual with learning disabilities and/or an autistic person reaches adulthood they are 'pushed' from Children's Services to Adult Services) be adapted into a 'pull' culture, wherein Children's services work with the individual to identify their goals and preferred activities, and work with Adult Services to develop identified skills in order to engage in activities of their choosing in adulthood. This means existing guidance on transitions ([NG43](#)) must be implemented more thoroughly, and services must ensure they cooperate to deliver on principles of person-centred transition.

2.3 - Dataset

THEME	DATA FROM SURVEY
Disruption to services and activities	All support which was already insubstantial disappeared.
	All services stopped- all their 'normal' ceased and increased their anxieties and challenging behaviours.
	His safe routines are what keeps him stable and lockdown completely dismantled these safe routines. This was very tense and challenging for all of us who support him.
	My sons day service (NAS) continued throughout to support my son - without them I feel we could not have survived! Given our particular circumstances he was one of very few but it showed they really understood how difficult it would be without that support – excellent
	The need for the normal "Day Services" is in question, clients are voting with their feet not to return to that "normal" now they have

The tendency to choose established/familiar services being brought into question	<p>been supported at home and other opportunities, ventures and experiencing have been made available to them.</p> <p>For us, taking children to have contact with parents away from the children's home has promoted more social activities</p> <p>A willingness from Commissioners, Adult Social Care and other provider to look at alternative to the "old style" of day services and actually apply the Care Act for its purpose, listen to those we support in helping them live a life of their choosing and not that from commissioners or ADC</p>
Flexibility and creativity of services	<p>One service user has family who are shielding and they didn't want him to come into day services. However, the family were unable to cope with him at home all the time as the behaviours are such that he requires 2-1 in services. We arranged to take him away for 3 night stays once a month to give the family a break. The day service staff take him as they know him well. We have been able to be more innovative during the pandemic.</p> <p>At the beginning we were able to move quickly and get things done, as the pandemic has gone on for longer, the old restrictions are coming back in place, more bureaucracy.</p>

3 - Housing

3.1 - Visiting relatives

The most prevalent issue for both families and staff/services related to residential care was visiting relatives. Individuals with learning disabilities living away from home, in residential care, supported living or ATUs found it difficult to adjust to the limited contact with family members, leading to a negative impact on well-being and an increase in challenging behaviour. For individuals who perhaps do not understand the pandemic, or reasons for social distancing, it was difficult for staff and parents to explain *“that the lack of physical contact is not because I don't love her or want to see her any more”*. Virtual visiting, or meeting under socially-distanced conditions, worked well for some, and provides a safe alternative to usual means of visits. However, we heard that staff in some homes may not have facilitated this proactively or as effectively as possible, even after requests, which could lead to individuals with learning disabilities feeling isolated or cut off. As with all discussions of digital communications, it should be considered that due to resources, access, or skills, virtual meetings are not necessarily appropriate, preferred or viable for all individuals and their families, and a person-centred approach and safe contact should be considered accordingly.

3.2 – Guidance & Testing

As mentioned previously, throughout the pandemic there has been a lack of specific and clear guidance for residential care services which support individuals with learning disabilities and/or autistic people. Many organisations developed their own protocols before government guidance was published, and specific government advice (for instance, the Supported Living Guidance published in August) lacked direct, clear information. As well as being late to arrive and insufficiently useful, guidance was also reportedly difficult to access and changed often. In the future, the government must ensure that individuals with learning disabilities, their families, and

those working to support them receive relevant, robust and timely guidance, created to meet the specific and unique needs of individuals with learning disabilities.

While suspension of visiting promoted safety during the earliest stages of the pandemic, many felt that if rapid testing had been made a priority for care homes, care workers, and families, it could have been of huge benefit. If testing had been made available, the negative impacts of isolation, loneliness and lack of contact with families could have been mitigated, and the failure to do so constitutes a neglect of the well-being and mental health needs of disabled individuals.

3.3 – Housing choice

During the pandemic, many families had to make a choice regarding where their relative would best reside – in full-time residential care, or full-time at home. For some parents, bringing their child home from a residential setting during the pandemic allowed them to reflect on how that setting had contributed to poor-wellbeing, and they subsequently decided to withdraw their learning disabled relative for full care at home. For others, bringing their relative home from a residential service led to challenges and a highly increased care load. One individual working in services was able to organise safe, overnight care 3 nights a month early in the pandemic, however claimed that *“at the beginning we were able to move quickly and get things done, as the pandemic has gone on for longer, the old restrictions are coming back in place, more bureaucracy.”*

Meanwhile, we heard from multiple families that, after requesting increased support provision for their relative with learning disabilities to meet the care needs of 24/7 at home care, they were offered support only in the form of a residential placement which had already been deemed inappropriate for their relative. This failure to ensure support is provided in the housing situation most preferred by the individual is a failure to meet the obligations of Building the Right Support, wherein it is noted that people should have a choice about where and with whom they live ([National Service Model, point 5](#)), and they should ‘expect, as people without a learning disability or autism expect, to live in their own homes’ ([NHS National Implementation Plan October 2015, point 3.1](#)). It reflects a lack of investment in appropriate flexible housing for people with learning disabilities and autistic people, which has been highlighted for 10 years during the Transforming Care programme

3.4 - Dataset

THEME	DATA FROM SURVEY
Visiting	Helping my daughter understand that the lack of physical contact is not because I don't love her or want to see her any more
	Not being able to see my daughter for around 3 months & frustration at the lack of contact on FaceTime etc., despite asking for this.
	Families not being able to visit their children at children's home, avoiding close contact with children who normally would seek affection from adults supportive them in the absence of parents- some like to hold hands or cuddle adults.

	<p>The residential staff could have been more proactive to facilitate video contact, and this plan and organise socially distanced visits outside.</p> <p>We regularly facetime parents and have facilitated visits for those who are able to socially distance</p>
Guidance & testing	<p>There was limited support or advice available from local authorities at the start of the pandemic. Most organisations I know had already developed their own plans and protocols before any official guidance was given out. Access to testing earlier would have been helpful and it is still a challenge in supported living services.</p> <p>Quicker guidance on restrictions for care homes/day services/supported living homes Free and accessible PPE from the start Adequate testing and results prioritised for care home and carers</p> <p>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.</p>
Benefits/challenges of different environment	<p>It has been wonderful to have our LD adult child back at home where they are happy and no longer stressed. Lockdown was the best thing that could have happened because it meant that our LD person couldn't go back to the care home which they hated to be in.</p> <p>Having family member return home during pandemic when behaviour became challenging. At times difficult to manage.</p> <p>It was nice to have family member at home for a few months</p> <p>One service user has family who are shielding and they didn't want him to come into day services. However, the family were unable to cope with him at home all the time as the behaviours are such that he requires 2-1 in services. We arranged to take him away for 3 night stays once a month to give the family a break. The day service staff take him as they know him well. We have been able to be more innovative during the pandemic.</p>
Inadequate support for housing which an individual actually prefers	<p>Not enough Carer support From Local Authority who has been refusing to provide more than 40 hours a week for someone who needs 2:1 support during day and 1:1 support at night. Instead the LA is funding a place in a care home for the person to return to for the last 6 months even though the LD adult is absolutely adamant that they don't want to go back there and an independent social worker has [written] to court saying that it is in LD's best interest to reside at their family home.</p> <p>I have been battling the Trust for a support package for my son for years without success despite his significant need, vulnerability and complexity. Covid has afforded those with services an excuse to continue to gatekeep the support he needs to manage. The Trust's management and ethos of putting children like my son into residential setting instead of offering support to keep the family unit together is the problem endemic and systemic to negate good practice.</p>

4 - Conclusions

This report has highlighted some key areas for consideration for those designing and delivering children and adult's social care services going forward, these include:

- **Implementing person-centredness as a key principle of the design and delivery of housing and social care services.** Individuals with learning disabilities need to be supported in the accommodation setting of their choosing, by staff who know the person well, and need to be supported to undertake the activities and access services most preferred by them. Many of the recommendations relating to person-centeredness already exist in guidance and best practice documents. The Care Act, NICE guidelines, Building the Right Support and the National Service Model outline the steps needed to make person-centred social care a reality, but these have been of limited success (due to a lack of investment of sufficient value to make recommendations a reality, under-provision of training/upskilling of support staff, and existing institutional cultures), meaning that person-centred social care for individuals with learning disabilities and autistic people is not standard.
- **The professionalisation of social care** is necessary to ensure that support staff are equipped to act with creativity and freedom, while being trusted to offer appropriate, regulated, and needs-sensitive support. The pandemic has shown that support staff – when equipped and empowered to do so – can act with creativity to ensure that appropriate services are provided and needs are met.
- **The importance of social care to individuals and families who access services must be reflected by decision makers.** The lack of available testing, PPE, and social-care-specific guidance led to the harmful suspension of visiting and social activities, and the toll of increased financial stress and care responsibilities has caused detriment to the wellbeing of these individuals and families. Maintaining these aspects of social care – and upholding the rights to a private and family life – should have been prioritised from the start, rather than being left as an afterthought.