



**The impact of the COVID-19 pandemic on adults  
with learning disabilities and / or autism, their  
family carers and service provision:  
a rapid learning review**

**MAY 2021**

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## **Introduction**

This report was commissioned in March 2021 by the ADASS COVID-19 Programme Team to reflect and build on the work of ADASS regions in supporting people living with learning disabilities and / or autism, and their carers during the COVID pandemic. It is a rapid qualitative review, using semi-structured interviews and a roundtable event to capture professional perspectives after a year of exceptional challenges.

Services have inevitably been in response mode. The report is designed to help them as they refocus on strategic change. Its findings suggest the emergence of new priorities and potential new ways of working for health and care systems, and for the communities of which they are part. It should be read alongside the ADASS/LGA outcomes and improvement framework: 'Supporting adults with learning disabilities to have better lives'.<sup>i</sup>

## **Recommendations**

### **Challenging inequalities**

1. ADASS should engage with DHSC and NHSE to ensure that the needs of people living with a learning disability are met fully by the next phase of the COVID vaccination programme, building on their experience to date.

### **Co-producing better support**

2. Councils and their sector partners should ensure that their planning out of lock down, and subsequent decision making reflects the voices of this community and works with it to co-produce better and more resilient support arrangements.
3. The pandemic fuelled innovation. Councils and their partners should learn the lessons from this and review commissioning and service provision in the light of what worked.
4. There is a need for greater awareness of learning disability and autism in the wider workforce eg housing that needs to be developed

### **Strategic re-alignment – from buildings and services to opportunity and community**

5. Councils and their sector partners should consider moving away from a heavy reliance on building-based services, investing instead in a more diverse set of opportunities for enablement and independence in communities. This shift will include appropriate use of new technologies and support for micro-providers.

### **Supporting independence**

6. Established opportunities for supported employment may reduce following the pandemic. Councils and their partners need to ensure these are sustained. This will require a stronger focus on transition planning into adulthood.

### **Sector-led improvement – promoting new ways of working**

7. National and regional professional and improvement organisations should move quickly to facilitate sector-led improvement processes, including benchmarking and guidance for place- and asset-based commissioning.

## **Executive Summary**

### **Views on the wider picture – equally valued?**

- The pandemic has brought into sharp focus the health and social inequalities faced by people in the learning disability and autism community. It should prompt some direct questions about parity of esteem for people with learning disabilities and autism and their families, and how much progress has really been made to prevent discrimination and ensure that the lives of people with learning disabilities and autism are valued equally with those of others in the wider community.
- The prevailing view amongst interviewees was that the impact of the pandemic on people with learning disabilities and / or autism and their families may not become clear for another 12+ months and most localities reported still being in 'response' mode (as at March 2021).
- A strong view emerged that the early stages of the national COVID-19 social care response was driven exclusively by a focus on older adults living in care homes – people with learning disability or autism were perceived to be an after-thought by government, reflected in the lateness and fragmentary nature of national guidance, testing and PPE relating to these groups of adults. This was considered a reflection of the long-standing weaker policy focus on this community more generally.
- In line with this national emphasis, proper account was not taken of the needs of people with a learning disability or autism in lockdown, including the feasibility of the containment measures and the greater impact these would have on their lives.

### **Workforce**

- In response to some of these issues, statutory and independent social care staff adopted an advocacy role for people with learning disabilities or autism nationally or in their areas to facilitate access to the vaccination programme. This involved helping to identify and prioritise individuals and enable the reasonable adjustments needed to support vaccination, developing passport schemes, and supplying 'official' letters in case of challenge.
- As social care and health staff were redeployed into different roles, a gap was exposed in the knowledge, skills and competencies around learning disability, autism and neurodiversity across the general social care, health care and housing workforce. In some localities this became an active risk management issue. It was also observed that low levels of workforce awareness and competency reinforce the social and health inequalities already faced by people with learning disabilities and autism.

### **Impact on people with learning disabilities and / or autism**

- The loss of contact with friends, daily activities and routines has exacerbated pre-existing health and wellbeing challenges for people with learning disabilities and / or autism. Increases in (or new) anxiety and depression were reported, alongside boredom and frustration.
- The degree of social isolation has been extreme in some instances, with anecdotal reports of some adults not leaving their homes until being vaccinated.
- Rapid shifts in guidelines, that resulted in sudden changes in provision, have been especially difficult for people with learning disabilities and autism to adapt to.
- There was an awareness that adults with the most complex and profound needs have been most challenging to support well during the pandemic, despite best intentions and efforts.

- Concerns were expressed about the impact these experiences have had, and may continue to have, on people's quality of life and personal potential.
- A particular concern highlighted during many of the interviews related to the future prospects for supported employment opportunities for people with a learning disability and/or autism. The economic impact of the pandemic on job opportunities in the coming years was seen as a significant risk to the availability and breadth of appropriate supported employment opportunities.
- The importance of re-focusing on transition planning for young adults moving into Adult Social Care provision was highlighted as an early priority by most localities.

### **Impact on informal family carers**

- Although many families coped initially and showed a stoicism that several interviewees found 'heroic', carer burnout has become more apparent particularly since January 2021 – i.e. from the point of the most recent national lockdown. Calls for support from families were reported as now becoming more urgent.
- Poor communication has been a commonly reported complaint by family carers.
- For some families, their experience during the pandemic has brought with it a realisation that the safety-net they relied on (often a combination of social care, family, and community support) was not adequate, albeit in the unprecedented conditions of a global pandemic.
- Similarly, the pandemic has highlighted the fragility of some care packages and support arrangements to families.
- A number of interviewees speculated that experiences over the last year may prompt families to reconsider how support is provided, opting for self-directed support and a personal budget in the future. Signs of this shift were noted by some localities.
- It is reported that family carers are uncertain and fearful that services will be withdrawn and / or not reinstated at their pre-pandemic levels. Many carers are aware of the financial pressures on public finances and are concerned that the appearance that families 'coped' during the pandemic may become a premise for reducing provision.

### **Joint service provision response**

- The primary focus of care and support since March 2020 has been on health, wellbeing, quality of life, and what matters to individuals. Despite the challenging operating environment and the restraints that everyone has been under, participants in the interviews felt that this was a positive, collective shift in mindset which they wanted to build on going forward.
- Initially, most day and short break/respice provision was stood down, followed by a gradual reintroduction of building-based services, at much reduced capacity (estimated as 30-40% or less of usual capacity), following risk assessment and light-touch repurposing. The criteria to access this provision was managed carefully to ensure that people with the highest level of need could be supported.
- Alternatives to usual day and respice provision typically included support offered virtually and via outreach e.g. weekly check-in calls for families, a digital wellbeing offer, 1:1 outreach support to facilitate daily exercise and social contact.

- Some areas reported continuation of new care package commissioning, ongoing development of Shared Lives models, Transforming Care hospital discharges, LeDeR (Learning Disabilities Mortality Reviews) and annual health checks - but these generally happened at a considerably reduced pace.
- Whilst day provision suffered the highest level of service disruption, residential and supported living settings appeared more stable. However, several interviewees noted that COVID outbreaks and deaths were seen in supported living settings and it was judged that part of the reason for this was that infection, prevention, control practices (IPC) and COVID secure advice was much more challenging to implement/enforce where people were living independently with support in their own homes. This could also be attributable to the slower focus on IPC, personal protective equipment (PPE) and other issues in communal living arrangements other than care homes.
- Some potentially important agile service changes have been possible. Examples include:
  - negotiated changes to accommodation and the creation of new emergency beds / apartments;
  - the creation of a new permanent team to conduct annual health checks, financed through Section 75 arrangements;
  - the introduction of a new complex care provider;
  - Shared Lives arrangements deployed as hospital step-down;
  - one locality has facilitated access to IAPT's (universal NHS provision of psychological therapies) for carers and people with a mild learning disability or autism.

### **Commissioner / provider relationships**

- The general view from commissioning colleagues is that relationships and mutual understanding between commissioners and providers have improved in the past year, which may be a helpful platform for market development in the future.
- Daily contact with providers was the norm among interviewees, as a form of support and contract management. Provider fora were increased to a weekly basis, alongside frequent bulletins and information sharing outside of these. Virtual care home visits were conducted in some areas, but formal quality assurance visits were widely reported to be on hold. This is a concern where homes are effectively 'closed institutions'.
- Supportive financial arrangements were developed with providers, with some examples of mutually agreed open-book approaches. Contractual payments were largely maintained or brought forward, and new contractual terms were developed. Additional financial assistance schemes were also introduced, such as compensatory payments and relief funds (for COVID-specific costs).

### **A strategically led recovery**

- Only two of the interviewees identified that they are working on an assumption that COVID-19 is here to stay in the medium to long-term and that it will become a strategic driver of change within the learning disability and autism sector, and adult social care more generally.
- All interviewees commented that seeing the impact of COVID on day services and short break / respite models in particular had focused and accelerated their thinking around the limitations and resilience of their pre-pandemic model of provision. The recurring theme across interviews was a

shift away from building-based support to buildings used as hubs / pods and increasing the availability of outreach.

- The need for a more mixed local learning disability and autism offer – including digital provision where this is appropriate and wanted by individuals as part of their support package – was seen to be the right direction of travel.
- Equally a shift away from offering ‘services’ towards facilitating meaningful activity and opportunity in the community, in line with adults’ preferences, emerged as a key message. However, this needs to be accompanied by a recommitment to strength-, asset-, place- and relationship-based practice as default principles for commissioning and practice.
- The shared experience of managing and adapting to COVID-19 was seen as a sound basis on which to work collaboratively with the provider market to reshape, diversify and flex what it is possible to offer for adults living with learning disabilities or autism – including the development of micro-providers / PAs.
- Many interviewees felt that an early priority in the next 12 months will be to actively engage with local people with learning disabilities and / or autism and family carers (across all generations) to understand their experiences during COVID-19 and develop local insight around need and preferences. It was suggested that this would also support collaborative re-engagement between individuals, families, services and the community.
- Having seen the impact of COVID-19 in the past year, many of the participants in the interviews said that it had reconfirmed for them that independence and a good quality of life may be less about services, and more about increasing capacity around early intervention and enabling life experiences - which must include full and timely preparation for adulthood. The potential features of an enablement approach are considered later in the report.

### **National advocacy and support**

- The interviews and the roundtable discussion flagged up the importance of national advocacy on behalf of and with people living with learning disabilities and / or autism, in the light of their experiences and the priority afforded to them during the pandemic to date. It was felt to be important that organisations such as ADASS and the CQC should be active in that national advocacy role. Given that the prevailing view from this research is that good uptake of the vaccine is seen as the primary method of reducing the risk of COVID-19 for people with a learning disability and / or autism, continued advocacy relating to the national vaccination programme and its uptake seems essential.
- Because all of the different teams supporting people living with a learning disability and autism across adult social care will be facing similar challenges, there was support for collaborative sector-led improvement approaches. These might, for example, benchmark good learning disability and autism commissioning and practice, with a focus on the enablers of independence.



## Narrative report

### Methodology

The brief for the rapid learning review was to understand the impact of the pandemic and what has been learned in the process of responding to it, primarily from the perspective of service leaders and commissioners in local government, but also taking into account the perspectives of people with learning disabilities and / or autism; their family carers; and staff working within the statutory social care sector, as commissioners, as social workers, and in some cases as in-house direct providers and their interactions with colleagues in the independent social care sector. The main lines of enquiry for the review were:

- How has the pandemic affected services for people with learning disabilities and / or autism, the people using them and their family carers?
- What adaptations and changes in practice or commissioning have evolved over the past 12 months?
- What needs to happen around provision for people with a learning disability and / or autism as we emerge from the COVID-19 containment measures and beyond?

The review included a stocktake of nationally published information which referenced learning disability and autism in relation to COVID-19. This provided a foundation for the interviews that constituted the main body of the research. Semi-structured interviews - 1:1 or in small groups – were held with service leaders and commissioners identified by ADASS. A roundtable discussion was hosted to sense-check the emerging findings.

6 regions participated in the interview stage and 7 regions were represented at the roundtable discussion. 3 regions also supplied additional pieces of research or development, which were used as supplementary evidence and to corroborate the findings from this largely qualitative review.

- **Yorkshire and Humber ADASS** learning disability and autism network developed and conducted its own research through a questionnaire which was distributed to all 15 authorities in the region, and which reported in June 2020. The intention was to use the findings to structure learning disability/autism/Transforming Care and transitions accountability and governance in the future.
- **East Midlands ADASS** commissioned a piece of work to examine the impact of COVID-19 on day opportunities and short breaks services for adults with learning disabilities and autism. The research took a 360-degree approach, taking in the perspectives of local authorities, people who use services, carers, and providers. This reported in September 2020 and has helped to highlight the differences between the perceptions of the main stakeholders in services.
- **North West ADASS** have focused on exploring health and social inequalities in the learning disability community, including the incidence of premature mortality prior to and during the pandemic. This work lead into a LeDeR (Learning Disabilities Mortality Review) Learning Workshop held in December 2020.

Additionally, a number of senior leads representing various strands of learning disability/autism policy and strategy were interviewed or participated in the roundtable, from the Local Government Association, national ADASS and the joint Care and Health Improvement Programme (CHIP) programme. A representative of the National Autistic Society was also interviewed in relation to their own research and analysis of the impact of COVID-19, covered by their 'Left Stranded' report.<sup>ii</sup>

Interviews with professionals in localities and at a regional level showed a detailed understanding of some of the individual challenges faced by people with a learning disability or autism and their

families during the pandemic. However, these were acknowledged to be professional perspectives, and not lived experience. Regrettably, the focus, time and resource limitations of this research did not allow for meaningful direct engagement with people with learning disabilities or autism and their families. To address this limitation, the report looked at a range of evidence and commentary from organisations who advocate for people with learning disabilities and / or autism and their families using participative methodologies and governance , including the East Midlands ADASS report and reports from Mencap<sup>iii</sup>, the National Autistic Society, Learning Disability England<sup>iv</sup>, and Carers UK<sup>v</sup>. Blogs<sup>vi</sup> written by family carers and their adult children with a learning disability or autism are also being collected and hosted by Warwick University, and were accessed to inform the review. Several British Medical Journal (BMJ) opinion pieces<sup>vii</sup> <sup>viii</sup> also provide insight based on advocacy or self-advocacy viewpoints.<sup>ix</sup>

## Overview of the national literature

There is a broad range of grey literature (non-peer reviewed) on the impact of the COVID-19 pandemic on adults from the learning disability and autism communities. This includes material from charities, voluntary and community organisations, professional and advisory groups and independent family advocates. There are also reports by statutory organisations and public bodies.

Learning Disability England<sup>x</sup> is working with researchers from 12 UK universities to gather an evidence base that will provide a first-hand account of the experiences of adults and families. The research in England is being led by Professor Richard Hastings from the University of Warwick and Professor Chris Hatton from Manchester Metropolitan University. UK-wide, the research will involve 1000 adults with a learning disability (400 from England) and 500 family carers (200 from England).

Key areas of concern emerging from the literature include:

- Organisations advocating for people with learning disabilities, autism and their family carers have presented a strong case that speaks to the palpable sense of isolation and abandonment experienced by some individuals and the challenges and difficult decisions taken by family carers to keep their adult children safe.
- Carers are fearful that services will be reinstated at a significantly reduced level of support .
- NICE rapid COVID-19 guidance on critical care <sup>xi</sup> issued in March 2020 advised that the clinical frailty scale (a tool normally used in older people's medicine) should be applied to all cases of hospital admission, but it did not initially distinguish that the guidance should not be applied to people with learning disabilities or stable long-term disabilities such as cerebral palsy.
- In March 2021 CQC reported<sup>xii</sup> on the inappropriate, blanket application of DNACPR orders/agreements for people with learning disability and Downs Syndrome.
- CQC also reported<sup>xiii</sup> that excess mortality amongst people with a learning disability increased by 134% when comparing the period 10 April to 15 May in 2019 and 2020.
- Media reports were critical of the prioritisation of people with a learning disability by the COVID vaccination programme, which did not seem appropriate given particularly high rates of mortality suffered by this group.
- Emerging findings<sup>xiv</sup> from the Learning Disability England supported research, highlight concerns around changes in support, health, vaccination, access to information and advice and varied experiences of using digital platforms.

## **Learning from the interviews**

### **a. The picture over the past 12 months**

Most interviewees acknowledged that local and regional systems are still in response mode, and many felt unsure about when a move into a recovery phase could happen. One suggestion was that this was more likely once the vaccination programme (both doses) for people with learning disability or autism had been completed.

There was a consistent account of a significant re-orientation of effort towards front-line service delivery, often with a dual focus on safety and wellbeing. This included a substantial process of redeployment of staff and duties across health and statutory and independent social care services. In turn, this highlighted a lack of skills and competencies around learning disability, autism and neurodiversity at a local system-level in some areas.

Much, though not all, of the strategic development around learning disability and autism provision at a locality level has ceased or slowed significantly over the past year. There were mixed views about when it will be possible to resume this work at previous levels.

There were consistent reports of the development of positive relationships and communication between commissioners and independent social care providers through what has been a challenging period for everyone involved. This was attributed to the crisis created by the pandemic, which mobilised a shared urgency, focus and motivation for partnership working and flexibility in localities. Some interviewees reported that it had been surprisingly easy to reach agreement on certain changes and adaptations with partner organisations, which was welcomed.

There was widespread agreement that day and short-break / respite provision had been most disrupted in terms of service continuity and availability. The perceptions from regional and locality teams was that residential care settings and supported living settings had generally been more stable, although IPC / COVID secure practices and workforce adaptations had inevitably been necessary. A number of localities reported that they felt that they had seen a disproportionate number of deaths in supported living settings (where adults live in their own home with a tenancy, or in small multi-occupancy tenancy homes) which they felt was linked to the challenges of enforcing COVID secure practices within someone's home environment.

### **b. The experiences of people with learning disabilities and / or autism**

The containment measures associated with the pandemic and the reduction of available social care and community provision formed the main focus of discussions about the direct impact on people with learning disabilities and / or autism. The loss of contact with friends, daily activities and routines, and the resulting social isolation were widely considered to have exacerbated pre-existing physical and mental health and wellbeing challenges for people with learning disabilities and / or autism. Increases in (or new) anxiety and depression were reported, alongside boredom and frustration. There was an awareness that adults with the most complex and profound needs have been the most challenging to support well during the pandemic, despite best intentions and efforts.

Concerns were expressed about the impact these experiences have had, and may continue to have, on people's quality of life and progress. A number of interviewees said that they had already heard reports from families and providers that some adults' confidence and sociability had regressed, and that there were rising levels of anxiety and some cases of depression.

A parallel concept, often discussed in relation to older adults is decompensation, which is used to describe the functional loss (cognitive, psychological and physical) that may be noticed after long

periods of illness or a prolonged stay in hospital. Discussion at the roundtable highlighted the importance of recognising the potential for similar impacts for people with learning disabilities and autism and the need to factor this into local recovery responses.

Rapid shifts in guidelines, that resulted in sudden changes in provision, have been especially difficult for people with learning disabilities and autism to adapt to and interviewees expected this to have deepened feelings of insecurity, impacting negatively on behaviour and levels of distress.

Looking to the future, the prospects for supported employment opportunities for people with learning disabilities and / or autism were highlighted as a key concern. There is a perceived risk that the invaluable role of supportive, appropriate employment opportunities for adults with learning disabilities and / or autism will be de-prioritised by employers in a climate of rising unemployment within the working age population and a competitive job market. Volunteering opportunities have often been a pathway into employment, but there is uncertainty about how fully those opportunities will be re-instated.

Transition planning for young adults moving into Adult Social Care provision was also highlighted as an early priority by most localities. Successful, well-planned transitions were seen to be part of the early intervention and enablement approach.

### **c. The experiences of family carers**

Interviewees expressed great admiration for family carers, recognising the extremely high burden of responsibility for care that had fallen on many of them, without any opportunity to prepare, especially for the families of adults who largely accessed day provision, which remains radically reduced in most localities.

Participants in the interviews recognised that providing current levels of care would not be sustainable for many families for much longer, and they reported that there had been an increase in requests for additional support/respice from family carers since the January 2021 lockdown. However, it was thought that deaths amongst people with a learning disability and / or autism may have been even higher if many families had not chosen to shield in March 2020.

Interviewees in one area reported uncertainty about a full return to services at their previous capacity, which will have implications for family carers, due to the need to maintain a COVID-secure environment for a precautionary period of time. The main enabler of a return to pre-pandemic levels of provision was thought to be high uptake of the vaccination programme amongst people with a learning disability or autism, and the care workers supporting them.

Whilst interviewees generally expressed a reasonable level of awareness about the issues faced by family carers, several interviewees highlighted a need to engage early with carers, in particular older parent carers, about their experiences over the past year, to understand their experiences and the impact on their wellbeing. The reports produced by Carers UK and the National Autistic Society (referenced in this report) provide compelling accounts of the experiences of family carers.

### **d. Adaptations in commissioning and service provision**

Most day and short break/respice provision was withdrawn at the beginning of the pandemic, in line with Government guidance, followed by a gradual reintroduction of building-based services at much reduced capacity. This offer was developed based on detailed risk assessments and practical changes that could be achieved quickly in agreement with providers. The criteria to access this provision was managed carefully and robustly to ensure that people with the highest level of need could be supported.

Alternatives to usual day and respite provision typically included support offered virtually and via outreach e.g. weekly check-in calls for families (by phone or virtually); a digital wellbeing offer which included attempting to maintain established friendships via zoom through activities or chat; and 1:1 outreach support to facilitate daily exercise and social contact. Care reviews were also conducted virtually where needed.

Some areas reported continuation of new care package commissioning, ongoing development of shared lives models, Transforming Care hospital discharges, LeDeR reviews and annual health checks - but these were generally achieved at a much slower pace.

Agile, strategic changes in provision were not widely reported in the interviews, but there are a number of examples from localities where this had been possible. The enabling factor may have been the maturity of joint commissioning arrangements and working relationships prior to the pandemic and unification behind a shared local vision.

Examples of some of these decisions include negotiated changes to the availability of residential or supported accommodation and the creation of new emergency places or beds/apartments; the introduction of a new complex care provider; and shared lives arrangements deployed as hospital step-down. One locality also responded to concerns about the mental health of people with mild learning disabilities or autism and family carers by facilitating their access to IAPTs (universal NHS provision of psychological therapies).

#### **e. Service providers and the market**

Although the interviews did not identify any immediate market failure concerns, it was acknowledged that as the flexibility and financial support afforded to providers during the last 12 months gradually reduces, it may uncover financial and sustainability risks within the local learning disability and autism provider market.

Market development was highlighted as a priority issue in numerous interviews, with the initial focus on reshaping day opportunities and short-breaks / respite. The recurring theme was to achieve a shift away from building-based support to buildings used as hubs/pods and / or increasing the availability of outreach. This was seen as a collaborative process with providers to diversify and flex what it is possible to offer for adults with learning disabilities or autism, including the development of micro-providers/PAs.

There was a general expectation that the mutual improvement in relationships and understanding between commissioners and providers, stimulated by the close working that became necessary during the pandemic, would facilitate this and lead to a greater degree of open-mindedness amongst providers who had previously been reluctant to change their business model and service offer. A number of interviewees reported that some providers had also engaged more positively with outcome-led thinking and provision.

The need for a more mixed local offer for people living with a learning disability and / or autism across day opportunities and short-breaks/respite was also raised and most localities reported that they saw value in including some digital provision, where this was appropriate and wanted by individuals as part of a wider support package. Anecdotal reports from some adults with learning disability and autism suggest that being able to engage with friends online in a managed, closed group from their own homes, was sometimes preferable to spending time in a noisy day centre where they did not always enjoy participating in the activity on offer.

#### **f. Strategic opportunities and priorities going forward**



The experience of COVID for many localities and regional representatives had led to a sharper focus on, and increased importance given to, the wellbeing and resilience of people who use services and their families, which they hoped to sustain in future commissioning and practice.

Equally a shift away from offering 'services' towards facilitating meaningful activity and opportunity in the community, in line with adults' preferences, emerged as a key message. This was associated with a recommitment to strength-, asset-, place- and relationship-based practice as the default principles for commissioning and practice. Several interviewees observed positively that the pandemic had created an opportunity to go 'back to basics' with social work and social care practice.

A number of interviewees hoped that the experiences during the pandemic would prompt a strategic shift towards increasing capacity around early intervention and enabling positive life experiences. The following examples demonstrate the potential features of a strategic and holistic approach:

- Well-planned transitions between children's and adults' social care services
- training and support for adults and families in early adulthood that helps to build independence, self-management skills and resilience. This may include helping adults with mild to moderate learning disabilities and autism to develop greater self-insight and confidence, using an assets-based approach
- travel training
- digital training
- developing a wide range of supported employment opportunities
- supporting a vibrant & inclusive community infrastructure and assets
- support geared towards maintaining a healthy lifestyle and good mental health
- facilitating social connections, friendships and relationships
- creating a good choice of housing options

Many interviewees felt that an early priority in the next 12 months will be to actively engage with local people living with learning disabilities and / or autism and family carers (across all generations) to understand their experiences during COVID-19 and develop local insight around need and preferences. It was suggested that this would also support collaborative re-engagement between individuals, families, services and the community.

### **Concluding comments**

The interviews with localities, regional and national leads which have informed this rapid learning review have created a rich and insightful evidence base. It can be used alongside local engagement and reflective practice, and national research, to create a holistic view of the impact of the COVID-19 pandemic on adults with learning disabilities and / or autism, and the families, communities and services that help to support them.

Research participants pointed to the need to take forward reforms within a wider perspective that acknowledges, understands and takes action on structural socio-economic and racial disadvantage. It is crucial to take account of these factors locally within local Joint Strategic Needs Assessments (JSNAs) and nationally with reference to nationally collated population and health and social care data sets.

## Appendix – Full list of participants

With thanks to all contributors for their time and willingness to engage in the review.

North West ADASS	Lia Chelminiak	NW ADASS Programme Manager
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		Commissioning Officer, Sunderland Council
	Ged Donkin Joanne Thynne	Commissioning Specialist, Sunderland Council
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East ADASS	Simon Froud	Essex CC Director Local Delivery & Regional Lead learning disability and autism
Yorkshire and Humber ADASS	Richard Parry	Kirklees DASS
	Hannah Brown	North Yorkshire CC, Service Development Manager
	Michelle Miles	North Yorkshire CC, Learning Disability and Autism Service Manager
	Helen Thirkell	North Yorkshire CC, Service Development Manager
East Midlands ADASS	Sue Wilson	Regional Improvement Programme Manager
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Local Government Association / CHIP Team	Sue Gale Rachel Carter	LGA Transforming Care Lead Adviser, Learning Disability and Autistic People
National Autistic Society	Mari Saeki	Project Lead



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- <sup>iii</sup> Mencap coronavirus information link <https://www.mencap.org.uk/advice-and-support/coronavirus-COVID-19>
- <sup>iv</sup> Learning Disability England coronavirus research link <https://www.learningdisabilityengland.org.uk/news/research-the-coronavirus-pandemic-and-the-lives-of-people-with-learning-disabilities/>
- <sup>v</sup> Carers UK, Caring Behind Closed Doors: Forgotten families in the coronavirus outbreak, April 2020 [https://www.carersuk.org/images/News\\_and\\_campaigns/Behind\\_Closed\\_Doors\\_2020/Caring\\_behind\\_closed\\_doors\\_April20\\_page\\_s\\_web\\_final.pdf](https://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_April20_page_s_web_final.pdf)
- <sup>vi</sup> Warwick University blogs by people with learning disabilities and their families <https://blogs.warwick.ac.uk/covidlearndisability/>
- <sup>vii</sup> BMJ opinion articles: <https://blogs.bmj.com/bmj/2020/09/01/covid-19-shows-that-the-lives-of-people-with-a-learning-disability-are-still-not-treated-as-equal/>
- <sup>viii</sup> <https://blogs.bmj.com/bmj/2021/03/18/people-with-learning-disabilities-are-equal-members-of-society-not-vulnerable-burdens/>
- <sup>ix</sup> Also of relevance, but published after this research was concluded, see Flynn, S. et al. (March 2021) Coronavirus and people with learning disabilities: Wave 1 results. Coventry: University of Warwick. [https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/results/wave1results/fullreport/coronavirus\\_and\\_people\\_with\\_learning\\_disabilities\\_study\\_wave\\_1\\_full\\_report\\_v\\_1.0\\_final.pdf](https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/results/wave1results/fullreport/coronavirus_and_people_with_learning_disabilities_study_wave_1_full_report_v_1.0_final.pdf)
- <sup>x</sup> Learning Disability England link describing UK-wide research underway <https://www.learningdisabilityengland.org.uk/news/research-the-coronavirus-pandemic-and-the-lives-of-people-with-learning-disabilities/>
- <sup>xi</sup> NICE rapid COVID guidance for critical care review link <https://www.nice.org.uk/news/article/nice-updates-rapid-covid-19-guideline-on-critical-care>
- <sup>xii</sup> CQC report Protect, respect, connect – decisions about living and dying well during COVID-19 <https://www.cqc.org.uk/news/releases/improved-oversight-reform-needed-pressures-pandemic-shine-light-inconsistent>
- <sup>xiii</sup> CQC data on deaths of people with a learning disability link <https://www.cqc.org.uk/news/stories/cqc-publishes-data-deaths-people-learning-disability>
- <sup>xiv</sup> [https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/resultsjanuary21/covid-19\\_key\\_issues\\_brief\\_report\\_25.2.21.pdf](https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/resultsjanuary21/covid-19_key_issues_brief_report_25.2.21.pdf)