

# Draft Final Report: National advisory group: People with Learning Disabilities and Autistic People

## 1. The key risks and concerns for people with learning disabilities, autistic people and their families

People with learning disabilities and autistic people are very diverse groups. While they have made great progress towards equality and living ordinary lives in recent decades, this has also been uneven and fragile. Prejudice and social exclusion remain daily experiences for too many people, and society's understanding of and respect for these communities has not kept pace with, for instance, growing awareness of mental ill health. COVID-19 has exposed and increased these inequalities.

There are many excellent social care providers and dedicated people working in the sector, but some areas of social care have lagged behind people's changing expectations, particularly as austerity has reduced social care budgets, and the social care sector was under huge pressure and fragile as COVID-19 hit<sup>1</sup>. Our recommendations, generated by a wide ranging advisory group, are based on the expectation of a fair and sustainable funding settlement for social care.

The COVID-19 crisis has jeopardised progress at every level. Disabled and autistic people are feeling ignored by society and left out of planning for a post COVID-19 world. Mortality rates have been unacceptably high. Many people in care homes and medical units have endured isolation from their families for long periods, while too many families have been left with no support at all. Many services have been reduced, paused or withdrawn and there is widespread anxiety that some may never return<sup>2</sup>. These extremes must be replaced with better targeting of limited resources on people living safely and well in a place they can call home. We have also seen people isolated and now digitally excluded as the world embraces technology which people can find inaccessible, confusing or unaffordable.

There is no data on death rates from COVID-19 for autistic people<sup>3</sup>, who are also excluded from LeDeR. We lack data<sup>4</sup> on reasons behind high rates of COVID-19 deaths for people with learning disabilities. For older people, group settings are

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<sup>1</sup> Public Accounts Committee July 29<sup>th</sup> 2020 (link) and NAO June 12<sup>th</sup> (link)

<sup>2</sup> Evidence drawn from Mencap survey of 12,000 people, LDE research and self-advocacy groups' submissions

<sup>3</sup> Unless they also have a learning disability

<sup>4</sup> There is a small sample analysis in *Deaths from COVID19 reviewed as part of the LeDeR programme*, University of Bristol

highly correlated with COVID-19 mortality<sup>5</sup>: we need to know if this is true for working age adults too. These data gaps must be addressed urgently: they reduce councils' and services' ability to plan and mean we do not have a full understanding of the current state of the social care system in all areas. The COVID-19 mortality rate for people with learning disabilities may be at least five times higher than expected, possibly approaching 10 times higher if age-adjusted<sup>6</sup>. For BAME communities, this could be exacerbated by pre-existing disproportionately higher mortality rates. People and families are reporting steep increases in mental ill health due to increased isolation, anxiety, and bereavement. Furthermore, Pre-COVID-19, pneumonia was the cause of death for 40% of people with learning disabilities. So the combined risks this winter are unacceptably high and urgent action is needed.

The Autism Act 2009 and subsequent statutory guidance makes supporting all autistic people a statutory responsibility. The Autism Act 10 Years On<sup>7</sup>, identified gaps in social care pre-COVID-19, which submissions to this group indicate have worsened since lockdown, including isolation exacerbated by digital exclusion and inaccessible information, and poorer access to low level support, and mental and physical health support for autistic people.

## 2. Priority actions

Despite the issues identified above, we have also seen how much people, families and some services have been able to achieve under huge pressure. This is not sustainable in the longer term and that resilience and creativity must not be used as justification for service cuts just as many individuals and families are approaching crisis point. It should provide the impetus to re-design services with people who use them. We must end the ethos of doing things for or to people, and instead embed the practice of coproduction into all COVID-19 planning both locally and nationally. This could require the creation of a cross-government champion for disabled people and certainly requires investment in self-advocacy and community organisations in every area. When done well, coproduction is more efficient: saving time, money, distress and even lives. Coproduction is the approach which should be taken to all the recommended actions in this report.

Our highest priority recommendations are that government should:

1. Commit to accessible guidance and communications for people with learning disabilities and autistic people, and their families, being issued with or very soon after all future COVID-19 guidance. This can be achieved by a)

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<sup>5</sup> Coronavirus outbreaks are up to 20 times more likely in large care homes  
<https://www.medrxiv.org/content/10.1101/2020.07.09.20149583v1>

<sup>6</sup> Analysis by PHE is in progress.

<sup>7</sup> Pears Foundation, NAS, APPG on Autism; Sept 2019, drawing on 12,500 individual submissions

coproducing a library of easy-read and accessible<sup>8</sup> COVID-19 information for people and services, as their local areas move in and out of lockdown, b) a national funded programme of digital inclusion to give people living at home or in services the right skills, equipment and broadband, and c) resourcing councils and CCGs to fund local self-advocacy and community groups to help people understand the rules and changes.

2. Restore, maintain and adapt the support for individuals and families already assessed as having eligible needs. This means ensuring councils and CCGs a) pause care, health or personal budget reviews during the period of service disruption, unless requested by the individual, b) make independent advocacy available wherever a change to support or an institutional care package is suggested, with support to identify and organise a community alternative for the same cost.
3. Urgently identify and provide the level of resources needed for councils or CCGs to financially stabilise provider organisations at risk of collapse; co-produce with providers a workforce plan for social care; expand funding for and availability of PPE, testing programmes and the Better Health in Care Homes programme from care homes to the whole provider sector<sup>9</sup> (and individual employers using direct payments), and grow the most effective and personalised forms of community support.
4. Reduce isolation and loneliness for people with learning disabilities, autistic people and their families, through a) expanding the reach of NHS and other volunteering programmes, and COVID-19 hubs, to people with learning disabilities and autistic people, and b) investing in a national awareness campaign encouraging and enabling communities and mutual aid groups to be more inclusive and supportive.
5. Reach individuals and families who don't receive social care support or organise their own, but who are isolated or in crisis. This means ensuring councils, CCGs and local VCSE partner organisations identify people not known to services to offer accessible information, timely needs assessments, and accessible mental health support.

In taking these actions, government should be mindful of the diversity of people with learning disabilities and autistic people, and particularly of groups who are most likely to be excluded, over-looked or at risk, who include:

- People with the most significant and multiple physical and mental health conditions and support needs
- People from black and minority ethnic (BAME) communities
- Families who are providing high levels of unpaid care and support

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<sup>8</sup> in line with the Accessible Information Standard

<sup>9</sup> Including care homes, home care, supported living, Shared Lives

- Young people in transition to adulthood
- People in large group settings
- People who have not previously been judged to have eligible social care needs
- Members of the LGBTQI+ community

Achieving these goals consistently and sustainably requires a new vision for health, care and support which is designed and controlled by individuals, supports whole families and households, valued and invested in as a key part of the economy, and commissioned and regulated for its outcomes. The key outcome is for people to live safe, full and meaningful lives in a place that feels like home as valued citizens of their communities.

### 3. Further important actions

In addition to the highest priority actions we have identified above, we discussed these important actions, some of which are cross-cutting rather than specific to our group:

1. Although £4bn has been allocated to the adult social care sector for COVID-19 response and maintaining financial stability, many argue this is not enough<sup>10</sup>. Local Authorities have not all delivered this in an effective and timely way<sup>11 12</sup>. This money must reach the care provider organisations it was allocated for and commissioners must be flexible to sustain providers which are facing variable demand and delivery challenges.
2. Support to increase digital skills, access and connections should be part of all support service specifications, and any services which pause face-to-face support should be expected to offer a digital alternative.
3. Fill in the gaps in accessible COVID-19 guidance, including guidance on public service changes, new laws and rules, employment support and getting benefits, and ensure that the expertise is in place to avoid any further lengthy gaps in producing key guidance.
4. A programme of work with BAME and LGBT organisations to understand the additional barriers facing people from those communities who have a learning disability or are autistic and to tackle the inequalities facing them during the pandemic. Little is known about the intersection of oppression, exclusion and higher risk factors and this needs to be understood, in order then to coproduce effective responses.
5. Research the risks facing those with profound and multiple disabilities. These groups may be facing particularly high risks of mortality and illness, so

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<sup>10</sup> Care England estimates that in May less than 40% of the extra-Covid-19 costs borne by learning disability and autism providers were met and 70% of all CCGs have not yet agreed to fund the extra Covid-19 costs of current Continuing Health Care (CHC) funded residents.

<sup>11</sup> The Public Accounts Committee expressed concern on 22 June.

<sup>12</sup> <https://www.gov.uk/government/publications/local-authority-covid-19-financial-impact-monitoring-information>

information is needed to understand this and what to do to reduce it, including through improving services.

6. Our remit was to focus on adult social care. We would like to be reassured that similar work is happening around parent and child support and we heard the need to get young people back into education safely in the Autumn to improve people's wellbeing and to reduce family carer breakdown and unemployment.
7. Review safeguarding, quality, wellbeing and mortality data in locked and institutional services during COVID-19 and ensuring people in locked environments are digitally connected to families and friends.
8. Raise awareness of and invest in the most resilient and creative community services which have kept people safe and well at home. Resource self-advocacy groups to co-design a COVID-19 proof support system to rely less on institutions and group settings.

We have available a full list of the themes of our group's discussions, and a list of all the actions suggested by the group and by the wider sector.

## 4. Health and integrated health/care issues

Our remit is to make recommendations on social care, but health and care are inextricably linked. The group was concerned that there have been an unprecedented number of DNACPRs made due to a person's learning disability and/or without clinicians undertaking the necessary Best Interest Meetings. An LDE survey found that 13 social care organisations saw an increase in blanket DNACPRs in March and April. Turning Point challenged 22 during April/May compared to around three per month beforehand<sup>13</sup>. We identified urgent actions for health partners to improve the health of people with learning disabilities and autistic people to reduce unnecessary deaths:

- analyse with urgency GP data on causes of death for autistic people and people with learning disabilities
- a campaign to reduce unacceptably high rates of obesity and diabetes, which increase COVID-19 risks
- reduce prescription of psychotropic medication, which may increase COVID-19 risks and urgently review medication for people with multiple prescribed medications which can carry multiple health risks
- outlawing 'learning disability' or 'autism' being given as a 'cause' of death or a reason for a DNACPR notice<sup>14</sup>.
- Working with self-advocacy groups, families and providers to ensure people

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<sup>13</sup> including a partially-sighted man with pneumonia wrongly diagnosed as coronavirus, who was discharged fully recovered from hospital after a brief stay, but found to have a DNACPR decision citing 'blindness and severe learning disabilities'.

<sup>14</sup> This was a recommendation of LeDeR, who commented in their recent annual report that, "by recording Down's syndrome for example as an underlying cause of death, it conceals the more specific causal sequence of events leading to the person's death. This was the case for 655 deaths."

with learning disabilities and autistic people, and their family carers and support workers, receive flu vaccinations<sup>15</sup>.

## 5. Making future planning inclusive and accessible

Despite great work by the experts by experience and self-advocacy organisations involved, this process was not fully inclusive and accessible, and lacked diversity, partly because of the very tight timescale. The government has in the past resourced a standing group of experts by experience, and we strongly recommend DHSC and partners build on existing coproduction initiatives such as Think Local, Act Personal's National Co-production Advisory Group, to ensure that a group of experts is already established and confident next time urgent support is sought to coproduce policy. A national group will only be effective if it can draw on well-resourced local groups led by people with learning disabilities, autistic people, and their families.

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<sup>15</sup> Three successive Learning Disability Mortality Review (LeDeR) annual reports identify that pneumonia and aspiration pneumonia are the most frequent conditions cited as Cause of Death for people with a learning disability.