

Recommendations for government from The Action Group for people with learning disabilities and autistic people, June 2021

Background

The COVID-19 Advisory Group for People with Learning Disabilities and Autistic People was formed in the summer of 2020 to help the Department for Health and Social Care to understand and respond to the impacts of COVID-19 on people with a learning disability and autistic people. It made recommendations and fed into the Social Care Taskforce report and Adult Social Care Winter Plan. The original recommendation and the government's response are collated [here](#). The group reconvened early in 2021 for three meetings, to look at the progress made on its recommendations and to update its advice to government. The group presented its updated findings to Care Minister Helen Whately MP and to Sir David Pearson, to feed into the Social Care Sector COVID-19 Stakeholder Group which he chairs, in May 2021.

This briefing is a record of the recommendations we made to the Minister and to national and local government. We would be grateful for support in circulating this briefing widely.

We would like to record our deep gratitude to all the members of the advisory group, listed in the appendix below, who have contributed so generously to the work of the group.

Rachel Moody, Expert by Experience.

Trevor Wright, Expert by Experience.

Alex Fox OBE, Chief Executive, Shared Lives Plus.

Co-chairs of the group.

Our three recommendations

We recognise that there has been a great deal of action and funding to address provider challenges such as PPE, testing and infection control and welcome the announcement that the current supply of free PPE to providers is to be continued after the projected end of provision in June 2021. We heard that this continues to be needed by a wide range of registered and non-registered social care services, including personal assistants, unpaid carers, family visitors to care homes, shared lives and supported living settings, and families supporting autistic people and people with a learning disability at home. We believe that this funding and support should continue for as long as it is needed.

We wish to highlight three recommendations on which we heard there is still much to do, and which will remain important as the country continues towards the end of pandemic restrictions.

1. Action on accessible information

Despite positive work by the DHSC, there remain a number of problems with accessible information:

- the quality of current accessible information can be poor, due to a lack of coproduction
- government departments apart from the DHSC do not always understand the value of producing accessible information
- The sheer volume of information makes finding accessible information very hard, particularly on big websites like those of the NHS, government, or BBC
- People lack the support they need to use accessible information

We recommend that government needs a stronger government-wide communications plan for making sure information is available quickly, meets accessible standards, is coproduced with people from diverse groups and is easy to find in one place. Also, that its dissemination is supported by a national coproduction group, and that resources are made available for local learning disability, autism and family carers organisations to use and share that information. This should be seen as an essential part of mainstream government communications strategies, not a separate or add-on task.

This would be a combined national and local approach, which funds and connects local organisations to distribute accessible information and to support people to use it. This needs to be coproduced with people from the start, issued as close to the mainstream information as possible, and should be the start of a new longer-term approach to working with big institutions like the BBC.

2. Action on day support and other services which stopped during the pandemic

There is now evidence that reduced day support has had a huge impact on people with learning disabilities and autistic people and their families who are worried that the services they relied on, some of which needed reform, may not return after the pandemic. We heard about the difficulties experienced by those preparing for adulthood due to reductions or suspension of education, and social and employment opportunities. This is reinforced by recent reports on the mental health difficulties of those under 30 during covid. Some families reported that their council questioned their ongoing need for services where they had been “managing” without them, despite the cumulative pressures of the last year.

We recommend that councils, with support and encouragement from government, should ensure everyone with eligible needs and their families who lost support during the pandemic is offered effective support that fully meets their assessed needs to live well in the community. This must be codesigned using direct payments and other personalised approaches and involve local self-advocacy and disabled person’s led and carer-led organisations. We welcome the autism strategy and wish to see a whole-life learning disability strategy alongside it. We would like to see an ambitious approach to community-based social care and the right to independent living as part of a long-term social care plan, with a strong re-commitment to personal and family choice.

3. Action on loneliness and exclusion

There is great concern about the welfare of groups of people with learning disabilities and autistic people who did not use state funded support pre-pandemic, particularly a) young people whose educational, employment and social needs have increased; b) people who did not have eligible needs for state services pre-pandemic but who may have significant support needs now; c) those who had eligible needs which were being met by their families now reaching crisis point.

We heard growing concern that loneliness and isolation has worsened through the lockdowns and that for some, this may lead to a worsening of their physical and mental wellbeing. We recommend a government funding plan for voluntary, community and social enterprise (VCSE) organisations to support funding people and families who may be at risk of crisis. There is a need for investment in community building in the short term, through the VCSE sector, and for the long-term social care reform plan to have a strong focus on communities, inclusion and the role of the VCSE sector.

We were glad to hear that the Minister was meeting the Minister for Loneliness, to explore the inclusion of people with learning disabilities and autistic people in the government's loneliness actions and plans. We recommend that Government should resource a programme of awareness and resources to support mainstream community and mutual aid groups to be more inclusive.

Inclusion and accessibility

We would like to record the results of our discussions with the Action Group on how to make such groups and work inclusive and accessible in future. Having two Experts by Experience (EBEs) as co-chairs was important and positive, and we found that we needed to draw on lived experience as well as academic research, and sector engagement in order to develop and sense-check our recommendations. We had significant challenges in making the work accessible, particularly when we were challenged to set up and work at pace last summer. EBEs saw some advantages in Zoom and remote working, which removes the demands and costs of travel, but also disadvantages, in terms of being able to participate equally. The group addressed earlier challenges by recruiting more EBEs and co-designing the meeting format with them, to include clearer ground rules, priority in speaking for them ahead of organisational representatives, and more use of break-out rooms. We asked organisations on the group to use their existing networks and forums to widen the conversation. There remained issues with complex rules and a lack of support for claiming expenses from the DHSC.

We recommend that groups of this kind co-design their meetings with Experts by Experience, but by far the best way for government to gain the insights and expertise of people with lived experience is to establish and resource standing groups who have already done the hard work of establishing how to work inclusively as a group when called upon for urgent work. Government could build on its investment in the National Coproduction Advisory Group of Think Local Act Personal, and the Health and Wellbeing Alliance to achieve this.

The co-chairs can be contacted via alex@sharedlivesplus.org.uk

Appendix: group members

- Rachel Moody – Lived experience co-chair
- Trevor Wright – Insight Autism CiC and co-chair
- Alex Fox – Shared Lives Plus and co-chair
- Penny Andrews – Independent self-advocate
- Zoe Armstrong – Director of Quality at Achieve Together
- Mark Bensiton – Head of Operations for Spectrum (Cornwall)
- Vanessa Bob – Independent self-advocate
- Samantha Clark – CEO of Learning Disability England
- Vivien Cooper – Founder of CBF
- James Cusack – CEO of Autistica
- Tom Elkington – Learning Disability Partnership Board, Leicester Council
- Edel Harris – CEO of Mencap
- Chris Hatton – learning disability and autism academic at Manchester Metropolitan University
- Roy Hayes – works for an information advice service in Halifax for people with disability and autistic people
- Jo Hough – Family carer and expert by experience, co-director of Inclusion East
- Lynn James – North west training and development team (learning disability and autism)
- Karina Johnson – Voyage Care
- Amy Kavanagh – Policy and Public Affairs Advisor at Sense
- Richard Kramer – CEO of Sense disability charity
- Michelle Larke – Lead Commissioner for learning disability at Leicester City Council
- Andrew Lee – Director of People First
- Erika Murigi – Head of Communications at VODG
- Andrew Reece – Head of Integrated learning disability service in Camden, London (represents ADASS Learning Disability and Autism Network)
- Dan Scorer – Policy and Public Affairs at Mencap
- Mary Simpson – Chair of the Autism Alliance
- Jordan Smith – Dimensions UK
- Zandrea Stewart – SOLVE Social Care & Health
- Sarah Yiannoulou – People First
- George Appleton – Senior Policy Advisor, Care England
- Jabeer Butt – Chief Executive, Race Equality Foundation
- Clive Parry – England Director, Association of Real Change
- Fazeela Hafejee – Mental Health Advisory Group

Other attendees

- David Pearson (standing invitation, Chair of wider Taskforce Stakeholder Group)
- Dave Nuttall (Deputy Director of Neurodiversity, Disabilities and Learning Disabilities, DHSC)
- Ruth Harrington (Deputy Director of Winter Delivery, DHSC)
- Sarah Richardson (Head of Dashboards and Outbreaks, DHSC)
- Sue North (Head of Children and Young People, NHS E/I Learning Disability and Autism Programme)