



Action Group for people with learning disabilities and autistic people

What we think the government should do

June 2021



Background

This group helps the government to know how Covid has affected people with learning disabilities and autism.

It advised on the Social Care Taskforce report and Adult Social Care Winter Plan.



It met again in early 2021 to look at progress and update its advice to government.



It presented this advice to Care Minister Helen Whately MP and Sir David Pearson.



This report tells you what the group advised.



We would like to thank all the members of the advisory group listed at the end.



What the Government needs to do

There has been lots of action and funding such as PPE, testing and isolating.

We think it is good that care providers will carry on getting free PPE.



This is needed by lots of services including:

- personal assistants
- unpaid carers
- family visitors to care homes
- shared lives and supported living settings
- families supporting people at home.



We think this funding should carry on for as long as it is needed.



We think there are 3 important areas where there is still much to do:



1. Action on accessible information

The government has done some good work on this but there are still problems:



- Quality of information can be poor when there is no coproduction



- Apart from the Department of Health and Social Care other parts of government do not value accessible information



- There is so much information on big websites like the NHS, government or the BBC that it's hard to find accessible information.



- People lack the support they need to use accessible information.



We need a plan for the whole government to make sure information is:

- quickly available
- meets standards
- coproduced with people from diverse groups
- easy to find in one place.



This needs to be coproduced with people from the start.



Local learning disability, autism and family carer groups should get funding to help them share this information and support people to use it.



This should be seen as an important part of keeping the public informed and not an add-on task.



2. Action on day support and other services which have stopped

There is evidence that cutting day support has had a big impact on people.



We worry that the services they relied on may not return.

We know that some of these services needed to improve.



We heard about the difficulties young people faced because of changes to education, social and employment opportunities.



There are reports on young people's mental health issues during covid.



Councils have used this to argue for taking away support long term.



We think councils should make sure everyone who lost support is offered support that fully meets their needs to live well in the community.



This must be codesigned using personalisation and involve self-advocacy and user-led organisations.



We welcome the autism strategy and want a learning disability strategy too.

We need a long-term plan for social care which supports a right to community-based social care and independent living.

3. Action on loneliness and being left out



We are worried about people with learning disabilities and autistic people who do not use state-funded support.

This group includes:

- young people whose education, employment and social needs have increased.
- people who did not need services before COVID but who may have support needs now
- people with care needs being met by their family who are now reaching crisis point.



We heard loneliness and isolation has got worse during the lockdowns.

It affects people's physical and mental wellbeing.



We need funding for voluntary organisations to support people and families who may be at risk.



This will help build communities and support inclusion.



We were glad to hear that the Minister was meeting the Minister for Loneliness to include of people with learning disabilities and autistic people in their plans



Government should provide funding to support mainstream community groups to be more inclusive.



Inclusion and accessibility

We would like to share how we made our group inclusive and accessible.



It was important to have 2 Experts by Experience as co-chairs.

We used lived experience as well as academic research and people who work in social care.



There were barriers to making the work accessible during lockdown.



There are some benefits to using Zoom such as people not having to travel and saving money.

But we also found it stops some people being able to take part equally.



To solve this we recruited more Experts and co-designed the meetings to include:

- Clearer ground rules
- Experts speaking ahead of others
- Using break-out rooms more.



We asked organisations on the group to use their networks to include more people in the work.



There were issues with complex rules and claiming expenses from the Department of Health and Social Care.



We think groups like ours should co-design their meetings with Experts by Experience.



The best way for government to work with people with lived experience is to fund existing groups who are already working inclusively and can be called upon for urgent work.



It could use the National Coproduction Advisory Group of Think Local Act Personal and the Health and Wellbeing Alliance.

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 - Director of Science at 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-Jenkinson - 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)