

Minutes of the APPG on Learning Disability's Meeting on Covid-19

9th June 2021, 15.00-16.30

Chair: Rt. Hon Mark Harper MP

Panel Speakers

- Andrew Lee, People First
- Gary Bourlet and Sam Clark, LD England
- Deven Pillay, Harrow Mencap
- Amanda Batten, Disabled Children's Partnership (DCP) and Contact

Other APPG Officers in attendance

- Baroness Hollins
- Lord Wigley
- Mike Wood MP

Other Parliamentarians in attendance

- Sally-Ann Hart MP
- Office of Lisa Cameron MP

Attendance

Approximately 53 people in total attended the meeting.

Themes (and summary) of Speaker's Contributions

Below is a short summary of the key themes from the panel. Some of these themes include further background information from the secretariat (Mencap).

Following these themes is a list of questions and areas of discussion the panel felt must be addressed by the Independent Inquiry into the COVID-19 pandemic.

1. Wellbeing and mental health

Andrew felt that throughout the pandemic a number of people with learning disabilities felt confused, scared and isolated. He explained that people felt cut off and forgotten about. One of the main contributing factors to this was that the Government daily briefings were not accessible or helpful for people with learning disabilities who were scared and did not have a lot of information on hand. Not only was the information not accessible, but when this was later rectified, it was not timely. The lack of effort in getting information out to people with learning difficulties left people feeling like they were not a priority.

Gary stated that during the pandemic he and many with learning disabilities experienced heightened feelings of fear, anxiety and uncertainty. He echoed Andrew's sentiment that family members, paid supporters and people with learning disabilities not feeling prioritised especially with PPE. He also highlighted that restrictions on day services and visiting restrictions during the pandemic only increased low levels of mental health and feelings of loneliness and isolation.

Deven touched on the feelings of loneliness/isolation, especially for people celebrating Ramadan/Eid, missing friends, grief. He also discussed the lack of appropriate responses and checks within the NHS for people with learning disabilities.

Amanda explained that services being slow or delayed had led to families feeling exhausted and burnt out during the pandemic. Stress and anxiety levels had rocketed, 42% parents with a child with learning disabilities had depression/poor mental health. She also explained that many children have lost vital a year of progress and siblings have had to become carers.

The DCP the Government's response to the pandemic must be holistic with a focus on health and wellbeing, reinstating therapies, respite and activities to tackle isolation. Amanda highlighted:

- ONS stats in 2020 highlighted the impact of COVID-19 on the wellbeing of people with a disability, with over a third (35%) of disabled adults reporting spending too much time alone compared to 19.9% of non-disabled adults.
- Furthermore, almost 1 in 10 adults with a disability reported often or always feeling lonely in the last seven days, compared with less than 1 in 20 non-disabled adults.
- The findings also showed that almost half (45%) of disabled adults said they are very worried about the effect that COVID-19 is having on their life compared with around a third (30%) of non-disabled adults, and nearly two-thirds (65%) reported that concerns around COVID-19 are affecting their well-being.¹

2. The digitisation of Government comms related to Covid-19 and GP appointments created exclusion

The panel highlighted problems of not having access to apps, catch up material for briefings etc. funding for free laptops. Support to use devices would have been helpful not only to receive information about the pandemic but also for virtual conversations and events.

Background

Throughout the pandemic there has been a lack of accessible information covering important changes to the law, public health measures, and changes to rights to access social care; even though the right to accessible information is required under the Care Act, the Equality Act, and in England, the NHS Accessible Information Standard.

Digital exclusion from accessible information meant that people have struggled at times to access health care. This includes routines GP appointments which were largely organised through apps and carried out over video call. Many people with learning disabilities did not know how to use the apps and could not get support to do that. This resulted in missed appointments.

1

<https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/articles/mappinglonelinessduringthecoronaviruspandemic/2021-04-07>

The recent JCHR report on the Government's response to COVID-19 said: *'It is important that there is clarity for the public in relation to any criminal laws, and particularly laws relating to the lockdown. **Information must be accessible to disabled people, especially those with cognitive impairments**'. They also said: 'More care must be taken by the Government to distinguish between advice, guidance and the law, in media announcements as well as in official online sources.'*²

3. Lack of clear accessible guidance/reasonable adjustments led to people not feeling prioritised or overlooked.

Andrew explained that the language used to refer to people with learning disabilities during the pandemic, included references to being 'vulnerable'. This was problematic as this view does not align with the view many people with learning disabilities have of themselves. Panellists went on to say Government messaging wasn't helpful or respectful, and that in fact it put people at greater risk because of the barriers and inequalities it reinforced.

Andrew stated that the current government communication systems and processes result in easy read being produced days or weeks after the main document when this should be done simultaneously.

Gary mentioned that many organisations had to provide their own form of easy read out of their own funding and resources due to the lack of clear easy read guidance from the government. This was made even more difficult with the release of new and updated guidance each week.

There was also a lot of misinformation regarding vaccines, people were being told not to take the vaccine, questioning what was in the vaccine, not being prioritised for vaccines.

Background

Mencap received funding from the Department of Health and Social Care to produce easy read materials and advice and support during the pandemic.

4. Delays and slow movement of services/community support

Gary argued that care in the community, where many people with learning disabilities reside, did not receive the same attention from the media as care homes for older people. Gary also states that during the re-opening of society and the economy people with learning disabilities will need more support to help build their confidence to get back into the community

Deven stated that from the parents/carers perspective- services are life-saving. During the pandemic however, services were cut or delayed and led to both carers and people with learning disabilities stuck at home 24/7.

² <https://committees.parliament.uk/publications/2649/documents/26914/default/>

Deven highlighted a lack of reasonable adjustments in providing services in supported living homes during the pandemic. People were locked in isolation in their own rooms. Supported living settings were not appropriate. There is a need for a more rigorous monitoring system which covers all services rather than limited scope of CQC. He also called for a more systems approach to service delivery which reflects how interconnected they are, COVID-19 exposed the existing flaws the issues in the system.

The DCP offered bespoke and safe services when others were shut. The impact of receiving services meant so much to families.

Background

To understand the experiences of family carers of people with a learning disability during the first lockdown of the pandemic, Mencap carried out a survey. From the 1,069 respondents:

- 7 in 10 (69%) people with a learning disability had their social care cut or reduced
- 4 in 5 (79%) family carers have been forced to take on more unpaid care for their family member
- 72% of families are scared of more cuts to social care happening in future³

And in November 2020, Mencap carried out a further survey to evaluate people's experience of social care during this lockdown and whether any changes had occurred between the two national lockdowns. From the 410 respondents:

- Nearly 9 in 10 people with a learning disability has not had all their social care support reinstated
- Almost 3 in 4 of respondents are worried that there more cuts to care packages to come
- Almost 2 in 3 of family members and carers said their loved one's support needs had increased
- Over 7 in 10 family members and carers said the amount of care and support they provided had increased
- Almost 1 in 2 of family members and carers said the amount of social care support their loved one receives from the local authority has decreased a lot (meaning they receive half or less than half the hours they received before the COVID-19 pandemic)

Key questions/ areas for the upcoming inquiry

1. Why was there so little engagement at a local level with self-advocacy groups for communication and support assistance?
2. Why did it take so long for the Government to recognise the disproportionate impact of the pandemic on PWLD and take action like prioritising vaccinations?
3. Why did the social care system fail at a time when it was needed most?
4. Why were individual rights reduced during the pandemic?
5. The Coronavirus Act significantly contributed to reducing rights through the use of Care Act Easements which some local authorities did use
6. What other impacts did the Coronavirus Act have on people with a learning disability?

³ <https://www.mencap.org.uk/get-involved/campaign-mencap/socialcarecrisis>

7. Why were health passports not being used?
8. We need to define what we mean by quality services?