

Questionnaire

UK COVID-19 Inquiry: Module 2 - Rule 9 Request to Mencap

Reference: M2/R9R/MENCAP/TJS

Please provide the following information:

1. A brief overview of the history, legal status and aims of the organisation or body. Please explain whether the work of the organisation or body is UK wide, or is instead confined to England, Scotland, Wales or Northern Ireland only.

Mencap is a charity (charity number 222377 (England and Wales)) that was founded in 1946 by Judy Fryd, who was a parent of a child with a learning disability. We work across England, Wales and Northern Ireland. The charity exists to support people with a learning disability and their families. We do this both through being a provider of social care support to around 4,000 people with a learning disability, as well as providing a range of other services, such as employment support, and the provision of advice and information services. We also campaign with and on behalf of people with a learning disability and their families and seek to engage with government policy development, as well as the legislative process to achieve positive change and inclusion of people with a learning disability in all aspects of life and service provision.

2. A brief description of the group(s) which the organisation or body supports or represents.

The charity exists to support people with a learning disability and their families. Across the UK there are 1.5 million people with a learning disability. A learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life. People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people. There are different types of learning disability, which can be mild, moderate, severe or profound. In all cases a learning disability is lifelong.

People with a severe learning disability or profound and multiple learning disability (PMLD), will need more care and support with areas such as mobility, personal care and communication. People with a moderate learning disability may also need support in these areas, but not definitely.

3. A brief overview of the work of the organisation or body in supporting or representing the relevant group(s) between January 2020 and Spring 2022 as it relates to the response to Covid-19 of (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive.

UK Government

Mencap's primary engagement with the UK government was through the Department for Health and Social Care and its agencies, such as the (now) UKHSA, formerly Public Health England. We sought to engage with officials and 'Covid cells' producing guidance on a wide range of areas from the very start of the pandemic, to ensure that the Equality Act was adhered to and that the needs of people with a learning disability were built into Covid related guidance and policy. Some areas of engagement were-

Supporting

- Mencap secured a £500,000 grant from DHSC for the provision of information and advice support on covid related matters for people with a learning disability and their families. We

- doubled our helpline staff numbers through staff redeployment, extended our opening hours, and developed working groups to produce 'easy read' accessible information on all aspects of current and rapidly changing government public facing covid related guidance.
- We used intelligence from enquiries to our helpline to inform questions and challenges we put to the UK government, addressing issues coming up in our contact with the public. In particular, we followed up on inquiries we received about how staff teams could support people with a Learning Disability who could not go out on their own, and noted the need for official letters for staff teams setting out what their roles were in case they were stopped by authorities.
- We supported our network of over 300 independent local groups to advise and support their members based on the knowledge and intelligence we gathered from our participation in national level groups run by government agencies.
- We undertook all measures possible to keep safe the 4,000 people we support directly in Mencap's care services, using creative approaches to engage and support people living through lockdowns, balancing people's human rights (for example their Article 8 right to family life) with highly restrictive government guidance.

Representing

- We successfully made representations for reasonable adjustments to the restrictions on distance travelled and the number of times that exercise could be taken in a day, recognising that many people with a learning disability would be with support staff, and therefore legitimately in a group.
- Asking the government to recognise supported living settings for people with a learning disability within their provision and planning for wider 'care homes', eg in relation to PPE, staff Covid testing and vaccination.
- Seeking reasonable adjustments to both hospital visiting and ambulance service guidance, so that people with a learning disability could be accompanied/visited in hospital by family or support staff, especially where the person was not able to communicate directly with health care staff.
- Raising serious concerns about NICE guidance in relation to the use of DNACPR notices for disabled people of working age, as well as the issuing by many GP practices of letters to care settings advising staff not to take residents with Covid to hospital, claiming they would not be prioritised for treatment. We called for and contributed to CQC's investigation into use of DNACPR.
- Reviewing criteria used by the JCVI in relation to priority groups for vaccination, and ensuring that people with a learning disability were, as a group, fully included, based on PHE and ONS data on high rates of deaths from Covid amongst people with a learning disability which clearly made the case for their inclusion. We were in direct contact with JCVI and PHE, as well as launching a public campaign around this.
- Monitoring the use of Care Act easements, and advising families on lawful practice under the easements.

4. A list of any articles or reports the organisation or body has published or contributed to, and/or evidence it has given (for example to Parliamentary Select Committees) regarding the impact on the group(s) which the organisation or body supports or represents of the response to Covid-19 by (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive. Please include links to those documents where possible.

- **Public Accounts Select Committee**, 'Covid-19: Supporting the vulnerable during lockdown', written submission, <https://committees.parliament.uk/writtenevidence/22724/pdf/>

- **Joint Committee on Human Rights**, 'The Government's response to Covid-19: human rights implications', written submission from Mencap and Challenging Behaviour Foundation: <https://committees.parliament.uk/writtenevidence/9281/pdf/>
- **House of Lords, Covid-19 Committee** inquiry into 'Life Beyond Covid', written evidence: <https://committees.parliament.uk/writtenevidence/10491/pdf/>
- **Barriers to healthcare for people with a learning disability during the pandemic** (Mencap research and policy report): https://www.mencap.org.uk/sites/default/files/2020-12/MyHealthMyLife_COVID%20report.pdf

5. The view of the organisation or body as to whether the group(s) it supports or represents was adequately considered when decisions about the response to Covid-19 were made by (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive. Please also explain the reasons for the view expressed by the organisation or body in this respect.

It is the organisation's view that people with a learning disability were not adequately considered when decisions about the response to Covid-19 were made by the UK government. This lack of consideration manifested in a number of ways-

- Rushed and closed drafting by 'Covid cells' of national guidance on Covid related restrictions, without adequate rapid engagement/consultation with relevant stakeholders to work through unintended consequences, unforeseen issues and implications relating to the Equality Act 2010.
- An ongoing lack of awareness and understanding by Ministers, and officials (many of whom were drafted in from other government departments at short notice) relating to the ways in which people with a learning disability are supported. This was particularly the case in relation to the repeated failure of the UK government to understand and provide for the specific needs of the supported living sector, which was largely forgotten when government considered the overall sector it called 'care homes'.
- Guidance and policy in relation to healthcare caused huge anxiety and distress for people with a learning disability and their families, due to blanket restrictions on visiting hospital settings, or accompanying disabled people in ambulances. This was also the case in relation to the wholesale move to online GP appointments, which as a policy did not adequately consider reasonable adjustments needed for people with a learning disability.
- Policy and practice relating to the use of DNACPR orders and advance decision making about treatment was deeply worrying and amounted to systematic disability discrimination.
- Decision making about access to the Covid-19 vaccine for people with a learning disability did not prove viable in practice, for example, in relation to the feasibility of trying to limit vaccine access just to those people with a learning disability on the GP Learning Disability Register, when 75% of people with a learning disability are not on registers.

6. Whether the organisation or body raised any concerns about the consideration being given to the group(s) which it supports or represents with (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive, when the Government(s) and/or Executive were making decisions about their response to Covid-19. Please provide a list of any such correspondence or meetings with the UK Government, Scottish Government, Welsh Government and/or the Northern Ireland Executive, including the dates on which the body or organisation wrote or such meetings were held, to whom the correspondence

was addressed or with whom the meeting was held, and any response received from the UK Government, Scottish Government, Welsh Government and/or Northern Ireland Executive addressing such concerns.

The organisation had extensive engagement with UK government officials and officials working in UK government/England agencies on all the above issues raised in our response to question 5. This engagement took the form of 1:1 meetings, participation in stakeholder engagement calls, emails to officials and in relation to some issues, such as use of DNACPR and access to the Covid-19 vaccine, speaking out in the national media and running campaigns. At this time we have not yet been able to put together all the correspondence, and calendar of meetings, so cannot share this with the Inquiry at this stage, but will be able to do so in due course. The Inquiry will be aware that Mencap will be applying for Core Participant status in respect of module 3 and hopes to assist and work with the Inquiry.

7. A brief summary of the views of the organisation or body as to any lessons, if any, that can be learned from any consideration which was given to the group(s) that the organisation or body supports or represents by (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive when they were making decisions about their response to Covid-19.

- Engagement with key stakeholders on development of guidance, even if at speed, is vital, to ensure that government understands the needs of specific groups and sectors, and the reality and complexities of a given area.
- Consideration of and acting on key legislation, such as the Equality Act 2010, is vital in terms of realising the impact of policy on people with protected characteristics and the potential for unforeseen discrimination and disadvantage.
- Officials, if drafted in from other parts of government, need to undertake rapid familiarisation and induction with key stakeholders in the sector(s) to which they are going to be making policy.
- Accessibility of government communications needs to be significantly improved, with a focus on the needs of people with a learning disability.
- During the pressures of a pandemic situation, government must retain focus on those groups who are most likely to experience vulnerability, and retain focus on and use of the significant body of evidence that already exists around discrimination and disadvantage in relation to people with a learning disability, for example, the Learning Disability Mortality Review.