

Written evidence submitted by The Down's Syndrome Association

The Down's Syndrome Association is a national charity focusing on all aspects of life for people who have Down's syndrome. Established in 1970, we have over 50 years' experience of supporting people who have Down's syndrome, their families and carers, and professionals working with them. We have around 20,000 members throughout England, Wales and Northern Ireland. The Association provides direct support to 70 affiliated local support groups, and a range of professionals from different agencies. The overarching aim of the organisation is to help people who have Down's syndrome lead full and rewarding lives.

We have a commitment to inclusive participation and work closely with a diverse group of individuals who have Down's syndrome called "Our Voice", who come together regularly to help shape and inform our work.

This submission to the Modernisation Committee's inquiry is in addition to our being part of a collective and wider response which has been submitted via the Royal College of Speech & Language Therapists.

1 - What topic(s) do you think the Modernisation Committee should prioritise and how do they link to one or more of the strategic aims set out in the Leader's memorandum?

The Modernisation Committee should prioritise plans to develop a stronger and more effective cross-party approach to inclusivity and accessibility, across the work of the House of Commons. This aim is aligned to a statement in the Committee's memorandum, paragraph 23 that the:

'House of Commons is an organisation that looks open and accessible to people from all walks of life so the House of Commons is representative of the society which we serve.'

According to Mencap, using figures calculated from Public Health England (2016) and population data from the Office for National Statistics (2024), there are approximately 1.5 million people with a learning disability in the UK¹. Barriers to accessibility facing those with learning disabilities will vary between individuals, but many people with learning disabilities have a significantly reduced ability to understand new or complex information and will struggle to engage with complicated terminology and jargon. Therefore, the need for accessible, easier

¹ <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/how-common-learning-disability>

to understand information for all individuals, including those with learning disabilities, is essential.

People who have learning disabilities are excluded from much of what takes place in and of the House of Commons, due to inaccessible language, consultations and information – and we ask the Modernisation Committee to prioritise and examine this issue as they consider the next stage of reforms to House of Commons procedures, standards, and working practices.

2 - Why would the topic(s) benefit from the attention of the Modernisation Committee?

During the 2024 general election many people with Down's syndrome were part of a DSA campaign to promote better engagement at the ballot box of people with learning disabilities (undertaken alongside the wider My Vote My Voice² campaign supporting all people with learning disabilities):

'I think that the parliament is a very interesting topic. Work with the government and choosing your Prime Minister by voting in a General Election is doing great work.' - Adult with Down's syndrome.

We were told that people understood the importance of Parliament, the principles of how it is meant to work and that they wanted to engage with it:

'Parliament is big and interesting and very important. It's important because the decisions made in government affect every person in the country. It's where people go to talk about decisions, voting and elections.' - Adult with Down's syndrome.

'Parliament is a sector of the British government. No matter how many controversies there are, they are supposed to help this nation become a better country. It used to be wealthy landowners in parliament, but now it is local people, and that is better for representation.' - Adult with Down's syndrome.

However, alongside this we also know that often when people with learning disabilities have tried to engage with the day-to-day work of Parliament they have often been left confused and unclear about processes and procedures:

'I was saying about the rules kept changing and there wasn't Easy Read information straightaway which made it more confusing for people.' - person with learning disability (speaking about political decisions made during the Covid pandemic)³.

² <https://www.myvotemyvoice.org.uk/>

³ <https://www.voiceability.org/news/speak-out-visit-to-parliament-with-mencap-what-we-said>

In 2015 the Digital Democracy Commission was established due to a series of concerns about how Parliament conducted and communicated its work – with criticisms that *'the jargon and practices of the House can be alienating and the sheer weight of information about politics, now available, can act as a wall, keeping the citizen out of the mysterious world of Westminster.'*⁴

The Commission resulted in a series of recommendations including:

- Improving public understanding about politics and Parliament
- Reducing jargon and making parliamentary language more accessible
- Making it easier to find out what is going on in Parliament

However, nearly 10 years on from the work of this commission much of the work undertaken across the House of Commons, and how this work is communicated internally and externally, remains inaccessible to many people, but especially those with some degree of learning disability.

In 2022 a House of Commons Library Briefing Paper provided information about which groups in the UK are considered to be politically disengaged, and why - it stated:

*'People with disabilities have more negative attitudes to politics than people without disabilities. People with disabilities that limit their activities a little (rather than a lot) are more likely to engage in political activities and to vote. People with disabilities are underrepresented in local government and Parliament.'*⁵

We ask that the Modernisation Committee investigate the wider practices and processes across Parliament, with the aim of undertaking a significant review in order that key parliamentary processes are adapted and delivered in a more accessible way, including:

- All government consultations
- Key government announcements
- National elections (including party manifestos)
- Language of staff on the parliamentary estate
- How constituents engage with their MP

Improving accessibility and inclusivity would not only make Parliament more effective, it would also ensure that Parliament – and the wider political process – is compliant with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), specifically Article 29⁶ on participation in political and public life.

⁴ <https://digitaldemocracy.parliament.uk/chapter/1-introduction>

⁵ <https://commonslibrary.parliament.uk/research-briefings/cbp-7501/>

⁶ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-29-participation-in-political-and-public-life.html>

3 - Are you aware of examples from other Parliaments relevant to the topic(s) which may be interesting for the Modernisation Committee to consider?

No response.

4 - Is there any existing work relevant to the topic(s) which you think the Modernisation Committee can build on?

In July 2022, the DHSC began a Call for Evidence to support consultation on the implementation of The Down Syndrome Act. The accessibility of this process was managed effectively. The team of civil servants working on this policy initiative met with representatives of the Down's Syndrome Association in the period leading up to the Call for Evidence being announced. Crucially, the Down's Syndrome Association also provided training for all relevant people involved from the DHSC, explaining in detail how best to make the process accessible and sharing decades of experience of being the lead support organisation for individuals who have Down's syndrome and their families.

The Down's Syndrome Association also helped the policy team shape an Easy Read document for the Call for Evidence which was launched at exactly the same time as the standard forms. One of the adults who has Down's syndrome who works with the Down's Syndrome Association was asked to make a short promotional film to encourage other people who have Down's syndrome to submit their evidence – this worked well. We also facilitated a series of accessible online meetings involving groups of adults who have Down's syndrome, and members of the DHSC team working on the consultation came to these to collate feedback.

Conversely, the following year, in June 2023, there was a consultation on the Code of Practice to accompany the Oliver McGowan mandatory learning disability training (also very much connected to people who have a learning disability). This was handled in a very unsatisfactory manner and caused a good deal of frustration across the sector. There was no Easy Read version of the consultation at launch. After protests from learning disability organisations, including The Down's Syndrome Association, an Easy Read version was promised, but was significantly delayed, eventually appearing around 1 month later. This required policy makers to extend the consultation period.

Similarly in 2022 the consultation on the government's SEND Review green paper had to be extended by 3 weeks as there was a delay in providing accessible information linked to the consultation. Such delays or oversight in prioritising accessibility (even within consultation

processes specifically about Special Educational Needs and/or disability), and by extension the engagement of those with additional needs, very much sets the tone that people who need any sort of reasonable adjustment are in some way second class citizens, or an afterthought.

The Down's Syndrome Association is running a new programme – Listen, Include, Respect – which aims to support the strategic involvement and engagement of people with Learning Disabilities across different organisations. The programme uses guidelines which were developed by Inclusion International and Down Syndrome International – and over 1,500 people with intellectual disabilities and their families from almost 100 countries helped write them.

The Listen, Include, Respect (LIR) guidelines (<https://www.listenincluderespect.com/>) explain how organisations can meaningfully include people who have learning disabilities in their work. The Down's Syndrome Association can help you plan how to set up an effective focus group and how to recruit a diverse range of participants.

Co-written and delivered by trainers who have Down's syndrome, this support can enable organisations to look at key accessible processes:

- How to run an inclusive meeting
- How to develop effective Easy Read documents/resources
- How to provide reasonable adjustments for people who have learning disabilities

The Down's Syndrome Association would welcome the opportunity to adapt the programme and work with the Modernisation Committee, and other Parliamentary systems/individuals to examine how the processes of Parliament could be made more inclusive for people who have learning disabilities.

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