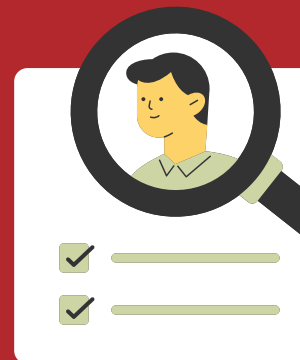


Learning Disability, Autism and Neurodivergence Bill

Consultation Response

From In Control Scotland, April 2024



The Learning Disability, Autism and Neurodivergence Bill (sometimes called the LDAN Bill) was open for consultation between December 2023 and April 2024. Below is a summary of In Control Scotland's response to this.

Definitions from the social model of disability



The consultation asked about respondent's opinions on who should be covered by the Bill. At In Control Scotland we believe in the social model of disability, which states that what makes someone disabled is not their medication or condition, but the attitudes and structures of society. People who are neurodivergent or have a learning disability face barriers to their full inclusion in society, these are not because of their perceived impairments or differences, but because society has failed to value them and to take their full selves into account.

Definitions, therefore, in the Bill should be inclusive of this, and should acknowledge the individual experiences of everyone with a learning disability or neurodivergence.

The removal of learning disability and Autism from legislation as mental disorders is crucial. This is out dated and must be changed.

Co-production of national and local strategies



There were a range of options presented on how local and national strategies should be developed, and what the guidance for these should look like. In Control Scotland believes

that people with lived experience must be involved in the development of these.

People with lived experience share their insights and expertise regularly, but rarely do they result in a real shift of power. This sometimes comes at a great personal cost as people share their traumas, but also there is rarely compensation for people's time if they are not taking part in the work in a paid role. This can lead to an unspoken power imbalance, with some voices seen as more valuable than others. For a true power shift to happen, people should be paid fairly for their time in developing these important strategies.

Training and communication



Our experience in implementing self-directed support tells us that too often training focuses on process and does not get beneath the surface to what is important. This includes thinking about our shared purpose and values as people who are working to address inequality.

Mandatory training in topics like Autism awareness and effective communication is the minimum we should aspire to. This should be combined with opportunities for active learning and continued development through peer support, reflective practice, and creative ways of stretching people's thinking. This should always be co-designed and co-delivered by people with lived experience.

Too often materials in easy read or large print come after the main documents are produced, meaning inclusive communication feels like an afterthought. Accessible information should be available to all people and at all times, and this should be tested with people to ensure it works well.

Planning and advocacy



Having someone walking alongside people and their families is incredibly important, and we see this as being crucial for people who are in long stay hospitals. Our work with the New Routes Home collaboration tells us that often there is confusion about who can do certain things with families, and people offering creative solutions can be missed out from important conversations.

New Routes Home works with families who have Autistic adult children that are stuck in hospital. If you would like to find out more about New Routes Home you can visit the

website here: <https://newrouteshome.wixsite.com/scotland>

Complaints processes are often seen as the only way to make change happen, but these are long, confusing, and can be a waste of resources.

There needs to be better availability of independent advocacy, which offers people a choice of advocates, but also a move to shared decision making and accountability rather than arguing over roles and responsibilities.

Complex care - Coming Home



The consultation outlined a set of options to increase accountability and scrutiny in bringing people home from long-stay hospitals. This is a subject we feel strongly about, as members of the New Routes Home collaboration.

We think that the second option described is the right one. This would involve a panel of people - which must include people with lived experience - who would oversee the processes of local authorities and carry out reviews to make sure they are doing what the Coming Home report asks of them. They would have the power make sure that local authorities make improvements. We think this option is the most likely to make change happen.

We also think that the Scottish Government could use networks like New Routes Home as part of the solution to ending institutionalisation of Autistic people.

Data

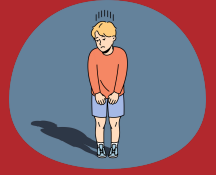


There were lots of proposals about how data could be collected, and the theme is spoken about in different areas of the consultation paper. We agree that collecting data is important, for example so that we know how many young people will be approaching transitions, or to understand how many people are stuck in hospital. We think that data on its own is not the solution. Data must be used and widely available for it to be meaningful. It should be clear about how data is used and shared for better planning, decision making, and accountability, and not just collected for no purpose.

There is an important gap in how we record data at the moment: often it is only collected when an action is taken, such as someone leaving school or getting a job. We think it is

important to understand when action is *not* taken too, as this can lead to high risk situations such as institutionalisation.

Restraint and seclusion



We understand the concerns that having restraint and seclusion in this Bill might put other people at risk as it is not covered in legislation for children and vulnerable adults. We know that current practice in restraint and seclusion can be harmful and we often hear that it is overused. We think that if there is to be further legislation or policy about its appropriate use across all groups then we support it being omitted from this Bill, but we worry that delays could cause further harm.

Education and transitions



We support all of the proposals around education, which include mandatory training for teachers, building strategies with education, and better data collection. We believe that inclusive education is only possible when everyone has the knowledge and skills they need to support every child, no matter their labels. This needs to be improved.

We know of many families who have been harmed by the way their children have been treated in school. This includes young people being secluded, having reduced timetables, or a poor curriculum. These families are often not told about changes to their child's school situation, so we think that improvement also needs to happen in the way that communication happens with families.

We know that good transitions are more likely when there is good planning, including person-centred plans. Ideally this should start at the age of around 14 for children with additional support needs. Good transitions need partnership working between teams in children's and adult's services. If a National Transitions to Adulthood Strategy is developed then it must be co-produced and there should be visibility on how it is being delivered locally.

Accountability



There were 5 proposals for increasing accountability, and we agree with 3 of these: introducing people with lived experience as champions and advocates within public bodies, better resourcing Disabled People's Organisations including Autistic People's Organisations, and ways of supporting better practice through tools, training, and guidance.

One of the proposals was to introduce a new Commissioner or a Commission. We are not convinced that having a Commissioner or Commission would make things better in the most meaningful way. We think that resource should be put towards the other 3 options as these will be the most likely to bring impact.

You can follow read the full consultation document and follow its progress through Parliament on the Scottish Government website here:

<https://www.gov.scot/publications/learning-disabilities-autism-neurodivergence-bill-consultation/>

Or contact the Scottish Government by emailing LDAN.Bill@gov.scot