includem

Learning Disability, Autism and Neurodiversity Bill Consultation April 2024

About includem:

includem are a Scottish charity that work with children, young people and families to help them transform their lives. We support children, young people and families to make positive life choices and progress towards the type of future they want to live.
To do this, we work with social services, schools and criminal justice services to identify which children, young people and families could benefit from our support. We then engage the child or young person and their family or carer to develop a package of support, tailored to their specific needs.

Our support is truly unique to each individual. There is no 'one size fits all' when it comes to helping children, young people and families to achieve positive outcomes.
We work with children and young people aged 0 – 26 across Scotland.

A lot of the children and young people we work with are neurodivergent, are waiting for an assessment, or are undergoing assessment and treatment. By far the biggest challenge for these children and young people is obtaining the support they require to engage with education.

The children, young people and families we work with, and their experiences have informed this response through conversations with colleagues across the organisation. To ensure appropriate allocation of resources we have only responded to questions that cover areas most important to the children, young people, and families we work with.

1. Scope & Terminology:

We support Proposal 2: 'People who are Neurodivergent/Neurodivergent People'

2. Going to Nursery and School:

What Do You Think?
- Which of these proposals do you agree with (if any), please tell us why?

We understand the need for better data collection and support proposals for a new requirement for education authorities and schools to include in their plans and reports an articulation of how the specific needs of neurodivergent pupils and pupils with learning disabilities have been considered and are being met. Similarly, we support the proposal that Children's Services Plan Annual Reports should include specific consideration of neurodivergent children and young people and children and young people with learning disabilities.

Despite support for these proposals, we heard clearly during our consultation phase that resources invested to meet reporting requirements should not hinder action on progress. We heard that while data collection and strategies can support oversight and analysis, the impact of this is not felt by children and young people who would rather see improvements made to support provision.

As an organisation dedicated to continued improvement and change, we support the need for training but want to highlight the challenges associated with this. Neurodivergent people have a diverse range of needs and experiences, making it difficult to provide training that adequately equips practitioners for the realities of practice. Additionally, training is only meaningful if accompanied by a culture aligned with the training, adequate resources to implement training, and continuous professional development. Training should be developed and delivered in partnership with children and young people who are neurodivergent, and their families.

- Which of these proposals do you not agree with (if any), please tell us why?
- Is there anything else that we should consider in relation to this:

Colleagues across the organisation had a lot of feedback based on conversations with children, young people and families they support. While there was a lot of positive feedback for the approach of the Bill, and the focus on the social, rather than the medical model, there was a lot of frustration about the lack of progress in successfully implementing existing legislation.

Most of the children and young people we support currently find it difficult to engage with education, despite additional support for learning provision in legislation and local strategies and duties. Despite their best intentions, parents who find it easier to navigate the bureaucratic processes and are aware of their rights manage to secure better support for their children than others who already face multiple barriers. This is further exacerbated by variable provisions in support and training of staff. Further data collection will highlight things we already know while children and young people are being failed.

We know, through our experiences of working with children and young people, that young people who have undiagnosed autism are at high risk of exclusion, poor mental health and poor attainment, further increasing the risk of being in conflict with the law. The lack of support for pre and post diagnostic support has significant negative impact on children, young people and their families. The bill, while well intentioned, will not have a significant impact on the lives of those we support.

3. Restraint and Seclusion

What do you think?

We appreciate the time and effort that has gone into developing the guidance. We want to be clear, however, that guidance is no replacement for comprehensive training and adequate resourcing in schools and other education and care settings. Professionals are currently expected, and make use of, restraint and seclusion without adequate training and support. Allowing this to continue is a child rights concern. While guidance is useful, it will not address the current challenges experienced by children, young people, their families and also practitioners.

The Committee on the Rights of the Child writes in General Comment no 8 that:

“The Committee recognizes that there are exceptional circumstances in which teachers and others, e.g. those working with children in institutions and with children in conflict with the law, may be confronted by dangerous behaviour which justifies the use of reasonable restraint to control it. Here too there is a clear distinction between the use of force motivated by the need to protect a child or others and the use of force to punish. The principle of the minimum necessary use of force for the shortest necessary period of time must always apply. Detailed guidance and training is also required, both to minimize the necessity to use restraint and to ensure that any methods used are safe and proportionate to the situation and do not involve the deliberate infliction of pain as a form of control.”

Despite this, restraint and seclusion are still experienced by too many children and young people. One of the young people we spoke to said:

“…sometimes the teachers are too strong, and it hurts and often it makes me more angry.”

More resources must be invested in training in alternative approaches to de-escalation as well as investment in early intervention for children and young people who require additional support to manage their emotions and behaviours. Exploring the statutory framework for this, in line with requirements of the United Nations Convention on the Rights of the Child (Incorporation)(Scotland) Act 2004, should be done as a matter of urgency, led by children and young people.

4. Health and Wellbeing

What Do You Think?

- Which of these proposals do you agree with (if any), please tell us why?
- Which of these proposals do you not agree with (if any), please tell us why?
- Is there anything else that we should consider in relation to this topic?

We have outlined our thinking regarding strategies and training above. In the first instance, resource should be channelled into improving implementation of current legislation. Better provision of accessible information and information in different formats is something we support. Information must be readily available, and easily accessible and should be provided alongside the opportunity to speak to a person if this is the best option for the person.

The biggest health challenge currently facing children and young people who are neurodivergent are the barriers to accessing mental health diagnosis, treatment and support. Waiting list for CAMHS have been widely reported on. Funding cuts are also reducing the availability of services when so many children and young people are in crisis.

We want to take this opportunity to highlight additional barriers children and young people face. Some of the young people we work with find it difficult to manage attendance at appointments because the letters or appointments are not accessible, they fail to attend because their lives are chaotic beyond their control. They fail to attend because they are vulnerable to negative influences, because they have bad experiences of services, because they experience stigma and feel shame. They also fail to attend precisely because they suffer from bad mental health.

Some of the children and young people who require CAMHS support are excluded from receiving this support because of the currently use drugs and/or alcohol. Young people tell us that they feel unable to stop using substances while their mental health is bad.

Finally, our experiences show us that families rarely get enough support to understand their child's diagnosis, management tools or strategies. Advocacy support for individuals who are neurodivergent, and their families, across areas of life is vital.