

Response from Carers Trust Scotland on behalf of young carers and unpaid adult carers to Scottish Government's Learning Disabilities, Autism and Neurodivergence Bill.

Introduction

Carers Trust Scotland welcomes the opportunity to submit a response on behalf of young carers and unpaid adult carers that we consulted with to the Learning Disability, Autism and Neurodivergence Bill. To inform this response, we undertook focus group and individual interview consultations with five young carers (under 18 years old) and eight unpaid adult carers (aged 50+) caring for a person with a learning disability, autism or neurodivergent people.

Carers Trust in Scotland works to transform the lives of unpaid carers.

We partner with our network of local carer organisations to provide funding and support, deliver innovative and evidence-based programmes and raise awareness and influence policy.

Carers Trust's vision is that unpaid carers are heard and valued, with access to support, advice and resources to enable them to live fulfilled lives.

Who Should the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill include?

During our consultation with young carers, they highlighted that the terminology being used to express the condition of the people they care for has changed over the years. They would like to have a part in the Bill where it would allow for terminology to evolve as further knowledge and diagnosis is identified. They felt that neurodivergent people should be included and that they should not need to wait for a diagnosis to start getting help. The overarching theme was that they are their family member or friend first and foremost.

"I don't like it when people call my brother different, we are all different in our own way, he just needs some more care." Young Carer, Secondary School Focus Group, April 2024.

"I really don't like the term special needs, older people talk like that when they talk about my brother. His needs aren't special and one day we might all need help, for now he just needs some additional support." Young Carer, Secondary School Focus Group, April 2024.

“I don’t think people should have to wait ages to have a name for what’s wrong with them, they should be able to start getting help and so should their family. My brother was told he had one thing and then it was actually another thing. I also had to wait so long for my CAHMS appointment.” Young Carer, Secondary School Focus Group, April 2024.

“I care for my brother, he has autism and ADHD.” Young Carer, Secondary School Focus Group, April 2024.

The young carers that we consulted with agreed with Proposal 2. However, the unpaid adult carers that we consulted with agreed with Proposal 3 as their preferred approach.

Statutory Strategies for Neurodivergence and Learning Disabilities

Through consultations with adult unpaid carers, it was clear there was an agreement with Proposal 5 to ensure that people with lived experience have to be involved in the development of the strategies. However, it was strongly expressed that this should be expanded to also include unpaid carers. It is important that people with lived experience and those who care for them are given access to participate in the development of strategies so that their experience and insight can help develop sustainable strategies and ensure a diversity of perspectives are considered and valued.

Unpaid adult carers highlighted the importance of ensuring that there is a requirement to perform evaluations, review strategies and ensure there is clear guidance so therefore agreed with Proposal 3 and Proposal 4. However, some argued that this should be undertaken every three years instead of five years, as this was agreed to be significant enough time to introduce and implement a strategy. But also enough time to highlight implementation challenges and ensure the strategy is still meeting the needs as intended.

Additionally, adult unpaid carers agreed with Proposal 6 regarding a new accountability system mechanism introduced by the Bill that should have a duty to review strategies and their effectiveness. However, during consultations, it was highlighted that there are currently accountability challenges with existing legislation. For example, with the Carers Act (Scotland), this piece of legislation is a national policy which is predominantly implemented at local authority level. Unpaid adult carers during the consultation expressed that when they have experienced challenges which fall under this piece of legislation, they feel as though there is a lack of accountability at both local and national level which has led to confusion and frustration. Due to this, some are fearful that they may experience similar challenges with this new Bill. To ensure this is avoided, it must be clearly stated how the new accountability mechanism would work and who assumes responsibility.

During consultation with young carers, they explained that they would like to be part of decision that will impact on them and the person they care for, such as a strategy. They felt that they and the person/people they care for should be included if it was going to affect them or their future.

The young people wanted information to be provided in a way that is easy to understand. The priority for young carers was that they receive help for them, their cared for person/people and their families. Some of the young carers had heard about local carers strategies for example, but were not sure how much benefit it had on them and their day-to-day life, especially with their stated experiences of some professionals not having an understanding of young carers.

Overall a national strategy received more support than local strategies. Views reflected by young carers and unpaid adult carers were that they believed a national strategy would ensure more consistency in support across Scotland.

Mandatory Training in the Public Sector

During consultation with young carers, they felt strongly that all public bodies and public sector staff should receive mandatory training, especially education professionals. They felt that not only those with lived experience should be included in the training but also the people that care for them. It was also highlighted that if a young person with a condition is identified and they have a sibling, then it should be enquired whether the sibling may have a caring role. Many young carers are not identified until they are at crisis point. Scottish Government recognises that there are at least 30,000 in Scotland, however, there are just over 6,000 young carers recorded in schools in Scotland. Academic research, Carers Trust research and survey work of local carer organisations has evidenced that around 10% of all children and young people have a caring role, which is much greater than the official statistic figure endorsed by Scottish Government. Early intervention would help identify more young carers and give them the support that they are entitled to, so they can live their life alongside caring.

“I think the person being cared for and the carer should be involved in the training.”
Young Carer, Secondary School Focus Group, April 2024.

“Input into training should include person with condition and the person who cares for them.” Young Carer, Secondary School Focus Group, April 2024.

“I believe mandatory training would help professionals know more about how to help my brother.” Young Carer, Secondary School Focus Group, April 2024.

Carers Trust Scotland would strongly recommend that any mandatory training as part of the Bill is fully funded (ringfenced) and resourced.

Inclusive Communications

When discussing inclusive communications with adult unpaid carers, it was generally agreed that there needed to be greater effort to reduce the number of barriers for people with lived experience and those who care for them. It was agreed that Proposal 1 and 2 would be beneficial in terms of improving inclusive communications and accessibility, as it was seen as a way to meaningfully address these barriers. However, they expressed that it is important that communications are not presented in condescending or patronising ways. Furthermore, there needs to be a variation in

the different forms of communications so that each person's needs are met, instead of being offered only a few variations and told to choose the one which suits them best even if it does not suit their needs. Unpaid adult carers were also in agreement with Proposal 4 to ensure an enforceable and consistent approach to Accessible Information Standard across Scotland.

Young carers highlighted the use of technology and asked why everything had to be in writing. They highlighted the need for videos and audio files that they could replay.

"I tried to write down all the complicated words the Doctor used when talking about my brother's medical condition so I could google them at home. I think I spelt them wrong as it was difficult to find them. I get so frustrated when I don't understand how to help him, a video for me and my brother would have been so much easier." Young Carer, Secondary School Focus Group, April 2024.

"They should communicate the best way for the cared for person." Young Carer, Secondary School Focus Group, April 2024.

Independent Advocacy

Adult unpaid carers agreed with Proposals 1 and 2 regarding independent advocacy. During consultations, unpaid adult carers highlighted that people with learning disabilities and neurodivergence require support to navigate the complexities of life; from finding employment, understanding the benefits system and intricacies of budgeting. For many it is a lifelong requirement to enable them to lead meaningful and fulfilling lives.

Social Care

Amongst adult unpaid carers, it was agreed there needed to be an improvement on inclusive communications and accessibility and therefore agreed with Proposal 3 for people living with learning disabilities to be able to request an alternative means of communication. However, there was concern that alternative means of communications could be presented in a way that could be in a condescending manner, so consideration should be given to ensure that alternative communication options are co-produced with people with lived experience and those who care for them to avoid this.

Additionally, there was a general agreement amongst adult unpaid carers with Proposal 2 for mandatory training for the health and social care workforce. This was seen as essential for those dealing directly with neurodivergent people and those with learning disabilities. One unpaid carer added that this training should be extended to staff working within social security; including Social Security Scotland.

Contact

Paul Traynor, Head of External Affairs, Carers Trust Scotland: ptraynor@carers.org

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