Lanarkshire
Carers

Scottish Government Learning Disabilities, Autism and Neurodivergence (LDAN) Bill Consultation Report

April 2024 | Lanarkshire Carers

Contents

Background

The Scottish Government are proposing a new Bill which aims to improve how people with Learning Disabilities, Autism or Neurodivergence access services in Scotland. This is being called the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill and “the objectives of this Bill are to better respect, protect and champion the rights of these groups, and to build a fairer Scotland for everyone” (*LDAN, from Scottish Government Consultation short guide*).

The Bill is looking at a wide variety of services offered across Scotland:

- Statutory Strategies
- Inclusive Communications
- Data
- Independent Advocacy
- Health and Wellbeing
- Mental Health and Capacity Law
- Social Care
- Housing and Independent Living
- Complex Care – Coming Home
- Relationships
- Employment
- Social Security
- Justice
- Restraint and seclusion
- Transport
- Education
- Transitions to adulthood
- Accountability
- Transport
- Access to digital technology

Lanarkshire Carers provide information, advice and support services to unpaid carers across Lanarkshire. We work with and for carers in Lanarkshire to develop and deliver services that make a positive difference to their lives. Lanarkshire Carers is a member-led organisation that supports meaningful carer involvement and participation locally and nationally. We encourage and empower carers to share their lived experiences by creating and developing opportunities for participation.

To support carers voices and views being heard and gathered in relation to the proposed LDAN Bill, Lanarkshire Carers facilitated different opportunities to meet carers individual needs. The responses gathered have informed this organisational response to the national consultation that will help build and shape the future of the LDAN Bill.

We focused on Full Members of Lanarkshire Carers and who have indicated their interest in being more involved with shaping and influencing services and invited them along to our LDAN consultation sessions. To engage as many carers as possible we had these in February and March, two in-person and one online. An in-person consultation was held for the Black, Asian and Ethnic Minority carers providing a more effective forum for interpretation needed in Urdu and Arabic. There was an overall attendance of 38 carers. To futher enhance our reach, we also created an online survey for carers who couldn’t attend the consultations. The survey ran from 8 to 24 March 2024 and received 58 responses.

Due to the size and scope of the Bill, the consultations and survey facilitated by Lanarkshire Carers focused on key areas which were directly relevant to the carers and the issues and services they are most likely to encounter. The areas chosen were:

- Identity and Definitions
- Accountability
- Employment
- Housing and Independent Living
- Social care and Complex Care
- Education

Identity and Definitions

Who should the Bill include?

Overall, carers felt that all groups of people with Learning Disabilities, Autism or Neurodivergence should be included in the LDAN Bill. With this being said, carers also identified the need for clarification about conditions covered by/ included in the Bill.

One area identified is with regards to the difference between a Learning Disability and a Learning Difficulty as this is not always clear. Suggestion that distinction and differentiations are required to provide adequate representation in the Bill and prevent the need to adapt or replace the Bill in the future. Only one carer responded with the opinion that they were unsure if all the conditions should be included in the same Bill.

A second area is the need for a more specific definition of Neurodivergent to best meet the needs of those with the conditions. Often the term Neurodivergent can be a grey area which results in generalisation and confusion about what is and isn't covered by the term.

Sample of carers quotes from the in-person consultations:
"Are the terms Learning Disabilities and Learning Difficulties going to be clarified?"

"Would you be excluded if you're still awaiting diagnosis?"

Sample of carers quotes from online survey responces:
"Carers should be included in case the cared for people do not have the capacity to share their lived experience."

"In my experience, the neurodivergent people who are currently most poorly served are those who appear 'less' neurodivergent. They are slipping through the net, being written off as badly behaved at school, don't show traits that e.g. the average employer may recognise and are not looked at looked out for in our health or education systems, despite their vulnerabilities. They are also potentially very sensitive about their condition and do not want to be 'lumped in' under a learning difficulties or learning disability umbrella"

Accountability

Who should be accountable for delivering the rights of the Bill?

All Carers in attendance to the in-person consultations and 39 who responded to the online survey agreed that a lived experience panel is vital to have a direct involvement with a shared responsibility for accountability, alongside either the local authority/ health and social care partnerships, the Scottish Government or a new commissioning body for delivering the rights outlined in the Bill. The carers who attended the in-person consultation had an equal split for accountability across the local authority/ health and social care partnerships and the Scottish Government.

Please see the breakdown below for the online survey results with 198 responses by 58 carers:

- Health and Social Care partnerships (40 responses, 20%)
- Lived Experience Panel (39 responses, 20%)
- Local Authorities (36 responses, 18%)

- Scottish Government (41 responses, 21%)
- A New Commissioning Body (26 responses, 13%)
- Preferred not to say or tick someone else (16 responses, 8%)

Sample of carers quotes from the in-person consultations:
"I think a lived experience panel...lived experience you know what it is, you've got it to a tee"

"I'm all for lived experience… what I think about accountability is that it should lie with health and social care or those who provide those services"

"They need to listen to people with lived experiences"

"I don't think social work should deliver it, it should be an independent body"

Sample of carers quotes from online survey responces:
"There needs to be a collaborative approach. We need the buy-in from the authorities but need people with lived experience to fully understand and meaningfully implement the Bill"

"The driving force for delivery should be the Lived Experience Panel. Many no doubt will have been in dispute with both the Health & Social Care Partnerships and Local Authorities about how they are not being listened to when it comes to the welfare of their loved ones."

"I feel accountability is imperative at every level and a devolved lived experience panel to ensure of implementation [is needed]."

"Ultimately the Scottish Government have overall responsibility for the "policing" of legislation, and this would be delivered by accountable partners such as local government (Social work/social care) and health/NHS. It is also vital that those with lived experience have a direct involvement as 'experts' in this area"

What do you think those accountable need to help them deliver the rights of the Bill?

Carers in consultations stated that access to the opinions of people with lived experience would be useful to help deliver the rights of the Bill in a meaningful and informed way. It was suggested by carers that this could be administered by an independent body made up of people with lived experience. This would make sure the message is not diluted through another commissioned body and that the information that decisions are based on is representative of those people being served by the Bill. All carers in attendance at the in-person consultations agreed to all of the below options being in place to help those held accountable deliver the rights of the Bill.

Please see the breakdown below for the online survey results with 200 responses by 58 carers:

- A National Strategy from Scottish Government (43 responses, 21%)
- Public Bodies such as Health and Social Care Partners and Local Authorities to produce Local Strategies (35 responses, 18%)
- That any National or Local Strategies produced are reviewed on a regular basis (36 responses, 18%)
- Those with Lived Experience are Equal Partners in producing any strategies and the reviews of them (44 responses, 22%)
- Better data to enforce the accountability of the rights of those who have a Learning Disability, Autism or are Neurodivergent (38 responses, 19%)
- Prefer not to say (4 responses, 2%)

Sample of carers quotes from the in-person consultations:
“Most definitely involvement from those with lived experience, who else better to advise!”

“Data needs to be accurate and up-to-date”

Sample of carers quotes from online survey responces:
“There should be clear procedures set and discussed with stakeholders”

“A charter detailing their legal responsibilities”

“There needs to be standardised practices that are reviewed periodically to ensure that wherever in Scotland you receive the same help. There needs to be clarity and full communication between bodies to stop people having to explain the same story time and time again to authorities who do not have the background information nor training to act in the neurodivergent person’s interest.”

“Scottish Government should produce a National strategy to provide a framework and standard for local strategies to meet and feed into”

“Regular review of strategies is needed to ensure that they are fit for purpose and needs are being met”

Do you think that those accountable should be required to create mandatory training for a greater awareness and understanding of the Bill?

Survey respondents and consultation attendees overwhelmingly agreed that those accountable should be required to create mandatory training for greater awareness and understanding of the Bill and people with Learning Disabilities, Autism and Neurodivergence across public bodies and that this should be done alongside those with lived experience.

The overall consensus was that training should be aimed at:

- Those who work within the Health and Social Care sector, who work directly with members of the public
- Those who work within the Third and Voluntary sectors, who work directly with members of the public
- Those who work within the Education sector

Conversations in our consultation sessions also highlighted the need for those in the medical profession to receive training regarding Learning Disabilities, Autism and Neurodivergence in order to improve the service and outcomes people with these conditions receive whilst interacting with health services, be that in hospitals, in local surgeries or at home.

Sample of carers quotes from the in-person consultations:
“Target education…there’s a lot of teachers in schools who don’t have the knowledge about these conditions, especially autism”

“We need to think of everyone we come in contact with, benefits agencies, GPs/ Health visitors and even housing”

Sample of carers quotes from online survey responces:

“[Training is needed because] The rise in individuals being diagnosed with neurodiverse conditions is escalating and can affect all sectors of society”

“Everyone. I had no real-life experience until my son was born. He doesn’t “look” autistic but some people assume it’s bad behaviour. Everyone should be given learning especially when dealing with the public.”

“Mandatory training is fine but where are the checks and balances to show that particularly Health & Social Care and Education are addressing issues raised in the Bill”

“Everyone has preconceptions and needs those challenged.”

“I note the comments about student teacher training requirements and think this should also relate to student social workers, nursing staff etc also. If this becomes a requirement to fulfil their degree/college course it is much more likely to be implemented.”

Employment

What would help in the Bill to make employment more accessible?

There was some consensus amongst those responding to the online survey that they agreed upon a need for (351 responses by 58 carers):

- More training opportunities for those who have a Learning Disability, Autism or are Neurodivergent (52 responses, 15%)
- For employers to have a greater awareness and understanding of Learning Disabilities, Autism and Neurodivergence (50 responses, 14%)
- For employers to make reasonable adjustments more easily understood for those who have a Learning Disability, Autism or are Neurodivergent and empowering them to ask for them (52 responses, 15%)
- For recruitment exercises to be more accessible and inclusive for those who have a Learning Disability, Autism or are Neurodivergent (50 responses, 14%)
- Inclusive communication and language which could be a video, an Easy Read paper or pictures to help those who have a Learning Disability, Autism or are Neurodivergent to better understand what is available and their options (51 responses, 14%)
- Better data to monitor the employment levels of those who have a learning disability, Autism or are Neurodivergent (45 responses, 13%)
- Independent Advocacy to ensure those who have a learning Disability, Autism or are Neurodivergent can access employment (48 responses, 14%)
- Prefer not to say (3 responses, 1%)

In the consultations, it was noted that the LDAN Bill could potentially clash with the Buckland Review of Autism employment and that existing employment rules are often interpreted by different government agencies and employers. Participants felt that an oversight advisory panel can ensure that rules are set out centrally, with no chance of different interpretations at the local level (be that council-wide or between localities within the same local authority) causing issues further down the line and preventing disparity across local authority areas. Furthermore, participants felt that this would also allow any issues or oversights to be rectified promptly without the need to pass new laws or make amendments to existing ones.

All carers in attendance at the in-person consultations agreed to all of the above options being required in the Bill to help make employment more accessible for those with LDAN.

Sample of carers quotes from the in-person consultations:
"Buckland review covers a lot of parts of our life – we need to predict clashes with this. The Bill could clash with practices of the DWP. I find the existing rules are interpreted by the establishment so you hear about postcode lotteries, one school doing one thing and another school does another thing, there needs to be an oversight panel that people can go to and get a uniform set of rules which are interpreted in the same way as all the establishments, whether that be in South Lanarkshire or Argyll and Bute etc. I can see discrepancies and people going to a lot of trouble to access their rights. An oversight advisory panel would allow things to be put right quickly rather then it go to laws are passed. If it could be interpreted centrally rather than by local authorities this would be better"

"Issues will be with the interpretation of this in each of the local Authorities similar to SDS and Carers Act"
"There needs to be a professional body to deal with this rather than social work, alongside those with lived experience"

"There is issues between localities in the same local authorities. Those of us that drive follow the same rules across the country and this should be the same."

"Employers use the excuse of Insurance"

"More job coaches and mentors in the workplace"

Sample of carers quotes from online survey responces:
"…a much better strategy [would be] using a multi-agency approach in order to deliver far reaching positive outcomes for disabled people and their carers"

"I don't believe the Bill will make employment more accessible as this is the remit of DWP and Job Centres to get more people into work. Statistics show that those with a disability are more than likely to be economically inactive and that those who are lucky to get work are either part time or volunteer. The working from home model has been successful in allowing those with physical disabilities to seek employment and others to maintain their job."

"From past experience, employers have no understanding of what is required to help people"

Housing and Independent Living

What would make it a more positive and accessible experience for those accessing housing and independent living?

With regards to Housing and Independent living, there was an agreement on what survey participants felt was the best approach as outlined below (283 Responses by 58 carers):

- More information and support providing advice, advocacy and guidance to those with Learning Disability, Autism or are Neurodivergent (50 responses, 18%)
- Making sure that local plans for those with Learning Disability, Autism or Neurodivergence, show how independent living is prioritised in housing processes (45 responses, 16%)
- Local Authority Housing Staff and Housing Associations should be required to undertake mandatory training to have a greater awareness and understanding of those with Learning Disability, Autism or Neurodivergence (48 responses, 17%)

- Inclusive communication and language which could be a video, an easy read papers or pictures to help those with Learning Disability, Autism or who are Neurodivergent better understand what is available and their options (44 responses, 15%)
- Independent Advocacy to ensure those with Learning Disability, Autism or who are Neurodivergent can access appropriate housing accommodation (50 responses, 18%)
- Better data to evidence that those who have Learning Disability, Autism or who are Neurodivergent do not have appropriate housing to meet their needs (43 responses, 15%)
- Prefer not to say (3 responses, 1%)

All carers in attendance at the in-person consultations agreed to all of the above options being required in the Bill to help make a more positive and accessible experience for those accessing housing and independent living.

Consultation participants highlighted key areas including the effects of social inclusivity and finances on how positive the experience of housing and independent living is. Participants noted that the local housing offered to people with Learning Disabilities, Autism and Neurodivergence is not ideal in terms of amenities and access to social inclusion, and without the ability to finance housing themselves, will be the only option available. This can then increase social isolation due to poor amenities, can affect access to friends and family and ultimately result in a poor standard of living and negatively impact other aspects of their lives.

Carers also shared that they can find it a lengthy process to receive self directed support direct payment option, if a need is identified, which can have an impact on the cared fors ability to live independently. Alongside Self directed support, carers have been asked what support they will continue to provide and it was noted from them that this defeats the purpose of the cared for living independently and the carer not having to undertake the caring role.

Some carers also noted the differences in how local authorities approach the topic of independent living. Some local authorities are encouraging the pooling of resources to allow people to live independently but this is often not what someone would prefer, given a choice. Ultimately, carers agreed that people with Learning Disabilities, Autism and Neurodiversity should be given the opportunity to choose where they live and who they live with in the same way that those without the conditions do.

Sample of carers quotes from the in-person consultations:
“I want to look at it from another angle, from a young adult who doesn’t have an SDS budget who works full time and is classed as disabled…she moved out when she was 19 and doesn’t recognise risk factors…no points at all relating to her disabilities. The whole point is she works full time but is exhausted once she has done that but if she doesn’t do that her life would be over. We were lucky in that her dad was able to put a deposit down and she ended up buying her little flat and the difference since then is unbelievable. Going forward I’m not sure my younger ones will secure an SDS budget for independent living and I’m just hoping there will be something in place…and things will move forward for everybody.”

“I live in North Lanarkshire and my son has his own home with support.” When asked if this is a positive experience, he would say “it’s is a yes and a no”…he wanted his own home and he is independent, and I think that’s wonderful, the hard bit was getting the budget in place because I was then asked how much unpaid support I was prepared to provide when he wanted to be independent and I thought how does that even make any sense… what young man wants their mum hanging about”

“I’m just thinking about North and South Lanarkshire – In South Lanarkshire they will have shared accommodation and will encourage people to pool their budgets and maybe live together whereas in North Lanarkshire they are more about living independently and in the community having your own home with the support but don’t necessarily have the budgets to go with that… I think all of these points are really important but there is also that wee bit about choice because some people will choose something totally different.”

Sample of carers quotes from online survey responces:
“Because a lot of people with Learning Disabilities, Autism and Neurodivergence are housed in poor socially deprived areas, open to vulnerabilities of society and ignored by the rest of society. I see it first hand, my son has difficulties and goes to a club on a Tuesday, many of those children that go for whatever reason are seeking other things, smoking, drinking, my son is vulnerable and is involved, we are not an inclusive society and we should be”

“A multi-agency approach, training and better communication will improve chances and opportunities for disabled people and their caregivers.”

“Housing has always been an issue for those who want to live independently. One of the main issues, I feel is down to finance and in some cases getting a care package in place which often causes the individual to miss out on a property. Each individual should have an assessment to determine the support they need to run their own home, this could be budgetary or health and wellbeing about cooking or making meals with also helpline advice should they be getting into difficulty. In addition, the individual should know what the care package will be before being offered a house.”

“Training for staff and advocacy are vital elements in helping people seeking their own home in suitable locations and suitable environments.”

“Everyone has the right to independent living”

“The issue with living independently for our neurodivergent children is not one of physical accessibility or adaptions. It’s the physically looking after themselves. They can cook, but can’t plan meals, and tidying up is an issue -typified by an inability to do something as seemingly simple as separating recycling - and have sensory issues with e.g. washing up - even loading a dishwasher! They will eventually load and operate a washing machine but rarely empty it at the end of a cycle. So in theory they appear imminently capable as they mask their way through assessments but fall apart when the demand is purely on them. This all leads to loss of self-worth and depression. As far as independent living goes, it is again the everyday demands that once triggered lead to a downward spiral in mood and generally being overwhelmed in their own home that is the issue.”

“Everyone has the right to adequate and suitable housing and if things can be refined and improved to make this accessible then it should be done.”

Social Care and Complex Care

What would make it a more positive and accessible experience for those accessing social care?

Survey participants were evenly split over the suggestions made in the Bill consultation as outlined below (245 responses by 58 carers):

- Health and Social Care staff should be required to undertake mandatory training to have a greater awareness and understanding of those who have a Learning Disability, Autism or are Neurodivergent (52 responses, 21%)
- Better signposting and awareness of what social care support is available (49 responses, 20%)
- A programme of monitoring and evaluation on how well the needs of those with Learning Disability, Autism or are Neurodivergent are being met (48 responses, 20%)
- Inclusive communication and language which could be a video, an Easy Read paper or pictures to help those who have a Learning Disability, Autism or are Neurodivergent to better understand what is available and their options (46 responses, 19%)
- Independent Advocacy to ensure those who have a Learning Disability, Autism or are Neurodivergent can access their rights (50 responses, 20%)

All carers in attendance at the in-person consultations agreed to all of the above options being required in the Bill to help make a more positive and accessible experience for those accessing social care.

Carers in the consultations and who responded to the survey had less to raise about this area of the Bill but it was questioned where funding was going to come from to impact upon the above suggestions given the amount of funding changes from social care in recent years. Training was also highlighted as an area which should be focused on, particularly in social care settings.

Respondents also advised that there is a need to place individuals at the heart of social care in order to ensure that their rights to be heard and supported are met and their conditions are understood. By placing people at the centre of what is happening, and understanding them and their needs, better care will follow, resulting in better outcomes, service and quality of life. By including people in discussions, they will know what is happening with their own situation which can help give them peace of mind and a sense of inclusion.

Sample of carers quotes from the in-person consultations:
"We need good conversations about both the needs of the carer and the needs of the cared for-never treat us like a unit"

"When it comes to ethnic minority groups we struggle with legal and other rights"

"Better understanding from professionals about ethnic minority groups and how that then fits in with LDAN"

Sample of carers quotes from online survey responces:
"From personal experience, some care providers' staff don't fully understand the complex emotional needs of people with learning disability. This can lead to confrontational responses to some simple situations from both the staff and the disabled person."

"Personally I have found that the biggest issue is getting the appropriate care package in place, this is where the advocate or family can get involved"

"My experience of HSC indicates that a great deal of training is required."

"It is imperative that the most stringent safeguards are in place and constantly monitored."

"Care can be complex at the best of times so refinement and clear pathways will serve LDAN people better and allow them to receive the care they need in a way that suits them and is tailored to them"

What would make it a more positive and accessible experience for those accessing a delayed hospital discharge or an inappropriate out of area placement?

Survey respondents were evenly split across the suggestions from the Bill consultation as outlined below (191 responses by 58 carers):

- Health and Social Care staff should be required to undertake mandatory training to have a greater awareness and understanding of those who have a Learning Disability, Autism or are Neurodivergent (47 responses, 25%)
- Better signposting and awareness of what social care support, housing, aids and adaptations and community based healthcare are available to those who have a Learning Disability, Autism or are Neurodivergent (45 responses, 24%)
- Local Authorities and Health and Social Care staff using the Dynamic Support Register for their area and to keep this updated (46 responses, 24%)
- The involvement of family, friends and unpaid carers in the planned discharge of those with Learning Disability, Autism or are Neurodivergent as set out in the Carers Scotland Act (2016) to ensure they are viewed as equal partners in care (EPIC) (46 responses. 24%)
- Prefer not to say or other (7 responses, 3%)

All carers in attendance at the in-person consultations agreed to all of the above options being required in the Bill to help make a more positive and accessible experience for those accessing a delayed hospital discharge or an inappropriate out of area placement.

A key running theme shared in the survey and the consultations was that carers need to be consulted, listened to and informed of plans before discharge from the hospital. Without the proper involvement of carers, the best outcomes cannot be achieved, resulting in an increased risk of readmission to the hospital or placements breaking down. Alongside this, carers feel that being informed of all support available would be beneficial and allow them to be equal partners in care as they and the cared for person have all the necessary to make well informed, educated choices.

Carers also shared their feelings that if adaptations need to be made to a home then there should be the option of a halfway house or other appropriate care facility being made available until the work has been carried out, rather than just waiting in hospital. It was made clear that care homes for the elderly should not be used for those people who are not of that age group.

Carers again highlighted the need for training of staff, and adequate financial investment in the supports offered to those being discharged from the hospital or being placed in out-of-area placement, to allow these transitions to be able to run effectively. This includes the supports being in place, particularly action plans, prior to the discharge or arrival at placement so there is no delay in the care being administered.

Sample of carers quotes from the in-person consultations:

“*Understanding is needed from all health professionals at every level about the additional support that we(carers) need to provide when a LDAN person is admitted to hospital and then discharged, it can be a very traumatic experience for them and us(carer)”*

"“When my mum was discharged to my care I was out of my depth and I wasn’t informed about anything to do with her care or discharge, she couldn’t walk and fell again and ended up back in. I think I should have been part of the conversation - I think it needs to be mandatory”

Sample of carers quotes from online survey responses:
“Carers can often be overlooked and it's imperative that they are listened to and respected and their views taken into account as carers, covered by legislation, and professionals need to be aware of this too.”

“Family/ carers must be seen as equal partners in care to avoid masking neurodivergents working the system to the advantage of their behaviours but ultimately the disadvantage of their predicament”

“It's essential to ensure good communication to promote rather than hinder the individuals covered by the remit of this Bill’s progress and have increased health and wellbeing through appropriate supports and care.”

“If things are in place before discharge it makes things easier for all concerned.”

“There’s not enough information out there for families”

“….more government investment is required in all sectors of the population to ensure the support is available after discharge from hospital.”

Education

Education was not an area that had been considered at first as part of the consultations but following the first consultation, this was an area carers were passionate about in terms of the impact on people with Learning Disabilities, Autism and Neurodivergence and the long-term effects this has on their lives.

Carers who responded to the online survey agreed on the following suggestions, once again in an even split, but their comments give a much wider and more comprehensive picture of their suggestions and thoughts on how this can be improved (308 responses by 58 carers):

- Educational staff should be required to undertake mandatory training to have a greater awareness and understanding of Learning Disability, Autism and Neurodivergent (46 responses, 15%)
- Initial student-teacher education and training should cover Learning Disability, Autism and Neurodivergence (45 responses, 15%)
- Plans in place to best support children and young people with Learning Disability, Autism or who are Neurodivergent during their time in education and report on how their development needs are being met (45 responses, 15%)
- The involvement of parents, carers or guardians in the planning of the support required and in place for those with Learning Disability, Autism or who are Neurodivergent (48 responses, 15%)
- Inclusive communication and language which could be a video, an Easy Read paper or pictures to help those who have a Learning Disability, Autism or are Neurodivergent to better understand what support and options are available (40 responses, 13%)
- Better data to demonstrate what progress has been made to improve wellbeing outcomes for those who with Learning Disability, Autism or who are Neurodivergent for children, young people and families living in that area (40 responses, 13%)
- Better data to show the true identity of those who have a Learning Disability, Autism or who are Neurodivergent in the local authorities to help build, shape and fund services (40 responses, 13%)
- Prefer not to say (4 responses, 1%)

All carers in attendance at the in-person consultations agreed to all of the above options being required in the Bill to help make a more positive and accessible experience for those accessing Education.

Several carers shared similar experiences regarding the diagnosis of Learning Disabilities, Autism and Neurodivergence whereby primary school teachers had questions about their child's abilities and possible conditions but due to their lack of knowledge the children didn't receive the appropriate support until reaching high school. This then meant that support which could have been put in place was not and the transition to high school was not managed in a way that was responsive to the child's needs. Again, due to the lack of knowledge and understanding of LDAN in the educational sector, the majority of carers noted their children's condition was seen as behaviour issues which has resulted in the children not receiving the right support and this has caused interruptions in their education.

Concerns were also raised around the isolation and exclusion that children with autism experience in school as a result of their condition and a lack of strategies in place to address these problems.

Sample of carers quotes from the in-person consultations:
"When a child starts primary school, would it be possible for the teachers to be in a better position to judge whether a child is falling behind or not? …. If there was something in the law that they are duty bound to tell you, even just suspicions, it would be much better and help us support our child."

"If they have a diagnosis in primary school it should be looked at to at least see if they would cope in high school"

"We need more people like the CAMHS worker who spotted my daughter had autism."

"I have one child who nearly took his own life aged 11, he's home-educated now as he has school-related PTSD… Just getting the right placement for my 12-year-old daughter who was out of school for 2+ years as she could not manage mainstream. Years and years of fighting!"

"The constant fight, I had to give up my own career. I don't think all these strategies and Bills will make a difference but I hope it will. Myself and parents like me have to fight but it's the children that are suffering"

"My child was moved from an ASN School to a mainstream school and she did not settle. She had been struggling in primary 6 and I didn't find out until primary 7. The teachers didn't know how to deal with my daughter. She has dyslexia, and has a place in the base – but when she failed a maths test she did it in the base and she did well. The base have put things in place for her like toilet pass, 5 minute pass, lift pass and they have been good but she is still being isolated at times. It should be the school's responsibility, not the base's. There should be something in place for children whether the diagnosis is there yet or not. The diagnosis doesn't mean support was there, its just a label."

"I was told by other people to get a plan in place so went for enhanced transition and my son's S1 was great. I naively thought that the support would continue in second year but it didn't and I was told by a classroom assistant a few weeks into S2 that they don't provide support past S1… At the start of every school year, you are back to square one and it's a big challenge again."

Sample of carers quotes from online survey responces:

"Education is aiming for an inclusive setting but simply don’t have the resources or staff to enable this. My son has been let down by being put to a mainstream setting and not coping. It’s not fair on him, his teacher or fellow pupils. The need for additional needs education is multiplying every year and the support is not there.”

“This group of Autistic and Neurodiverse individuals are currently being excluded, home-schooled or isolated in school. This is not the teacher's fault but the failure of both the Government and Local Authorities to address the problems. Budget cutbacks have seen support staff removed and one way of tackling challenging behaviour is to use exclusion notices rather than tackle the problem. One answer might be smaller classes for those in this group who are struggling along with access to all required support.”

“My son is now 30, the education he received at school was amazing but we have had 2 attempts at higher education and training, disasters!! At present on his third attempt. Please don’t let this be anyone else’s story”

Summary and Conclusion

Lanarkshire Carers wanted to respond to the proposed Scottish Government Learning Disabilities, Autism and Neurodivergence (LDAN) Bill with the views of carers. We sought this through consultation sessions and an online survey.

It is clear from the response we had to this work that this Bill is of interest to many of the people that engage with Lanarkshire Carers. They have shared their experiences, thoughts and ideas and we have tried to represent a summary of these in this report.

We plan to look at how our own organsation can also learn from this, explore staff learning and development further, our individual case managed support to carers and how we can represent and advocate on their behalf. We will also look at how our carer-led services can further respond to this for example, self-advocacy, SDS carers training and condition-specific work.

Lanarkshire Carers welcomes any follow up consultation/clarification work if this would be helpful and will respond to further carers engagements when these are announced. We are also committed to always feeding back to people the outcomes from our carers involvement activities. We will monitor the next stage of the Bill and provide updates to carers when these are published.