

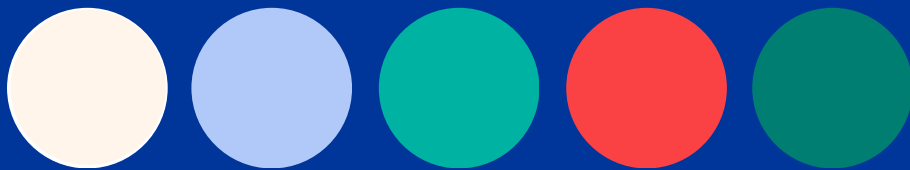


SCOTTISH AUTISM

Embracing difference,
leading change

Centre for
Practice
Policy and
Research

Seizing The Moment



Scottish Autism's Manifesto for Change
2026 Scottish Parliament Election



Foreword

Scottish Autism was founded in 1968 in Alloa by a group of parents concerned at the lack of services and support which existed for their children. They resolved to develop their own and over the six decades since, we have developed services which provide support to autistic people, their families and those who support them throughout their lives

Through our Centre for Practice, Policy & Research we seek to ensure that the most up to date knowledge of autism is applied to our work and to enable us to advocate for a society which recognises, understands and supports the needs of autistic people to enable them to lead happy, healthy and fulfilling lives.

The 2021-2026 Scottish Parliament has been one of missed opportunities. Following the 2021 election there was great hope for significant reforms to social care, of the delivery of a Learning Disabilities, Autism and Neurodivergence Bill and of progress to deliver better outcomes for autistic people across all policy areas and levels of government.

Sadly, these aspirations have not been realised,

the National Care Service Bill was fundamentally weakened and then eventually repackaged as a much more modest suite of reforms, delivered under the title of the Care Reform (Scotland) Bill.

The Learning Disabilities, Autism and Neurodivergence Bill was heavily consulted upon but then inexplicably parked, with work being undertaken instead to develop draft provisions ahead of the 2026 Scottish Parliament.

A Bill which would have improved transitions planning for disabled children and young people as they moved to adult services was not supported and we have seen worrying developments in terms of the loss of assessment and diagnostic pathways in many parts of Scotland.

We believe that the next Scottish Government must do more to deliver for autistic people, their families and those who support them and we have been listening to their views, concerns and priorities via the range of services which we deliver.

Our manifesto therefore highlights the five main areas where action could be most effective in delivering real and meaningful change and we ask Scotland's political parties to commit to supporting them.

Dorry McLaughlin
Chief Executive



“ We believe that the next Scottish Government must do more to deliver for autistic people, their families and those who support them. ”

Our Manifesto Asks

1

Commit to delivering the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill

2

Introduce a National Neurodevelopmental Pathway Guarantee

3

Improve support for autistic learners and an end to informal exclusions in education

4

Deliver a reformed social care sector where specialism is recognised, third sector providers are valued; and the workforce is appropriately rewarded

5

End the categorisation of autism as a mental disorder within the Mental Health (Scotland) Act

1

Commit to delivering the Learning Disabilities, Autism & Neurodivergence (LDAN) Bill

Autistic people and their families are entitled by law to timely and appropriate support, but all too often we hear from families who have to fight on multiple fronts for the support they need – whether that is a timely diagnosis, the accommodations that will mean proper inclusion in education, or community-based adult social care provision.

It was this evidence which prompted us, alongside Enable and National Autistic Society Scotland (NAS Scotland), to campaign for legislation to address the accountability gap across Scotland's public services. This, in turn, led to a commitment from the Scottish Government in 2021 to introduce a Learning Disabilities, Autism and Neurodivergence Bill which would introduce statutory strategies and mandatory training across a wide range of services and sectors, and which would deliver a means for public services to be held to account for failure to uphold the rights of autistic people.

It was, therefore, a source of immense disappointment to many autistic people and their families when the Scottish Government announced, after years of consultation, that the LDAN Bill would not be progressed before the end of the 2021-26 parliamentary session.

Many people had devoted significant amounts of time and energy to the scoping work and consultation process, as well as campaigning for the legislation to be introduced in the first place. To see it shelved by the Scottish Government, after many had shared their stories and experiences – often traumatic in nature – was interpreted by some as an indication that the improvements which the legislation could have brought about were not a priority for ministers.

“When I attended a hospital appointment the doctor I saw made me feel uncomfortable. Didn't have an understanding of my autism...They were very abrupt with me, making me feel more anxious and aggressive and caused me to have a meltdown. This drew attention from staff and patients, making me feel very upset and embarrassed. I was wearing my lanyard and autism card on show.”

Rich (autistic adult)

There was also a concern that the voices of autistic people were, once again, not being listened to by those in power. The risk is very real that many people will be less willing in future to contribute to consultations and legislative work, if they feel that it will not lead to meaningful change.

The Scottish Government has committed to consulting on the draft provisions for the Bill, which means the legislation will have achieved a level of readiness for introduction by the end of the 2021-26 Scottish Parliament.

We therefore believe that it should be a priority of the incoming Scottish Government to introduce and pass the LDAN Bill during its first legislative programme.



2

Introduce a National Neurodevelopmental Pathway Guarantee



We have witnessed significant and troubling developments in the area of assessment and diagnosis with adult pathways closed down in Aberdeenshire and Forth Valley, and child and adolescent pathways restricted in Tayside. There has also been a move across Scotland to remove young people awaiting an assessment for autism and ADHD from the CAMHS waiting lists unless they have a co-occurring mental health condition, and it is unclear how these assessments are to be fulfilled.

“Before and during the assessment nothing was offered but after the diagnosis (which was 4 years later) I was initially told that no help was available.”

Anonymous response to
Diagnosis Survey

Diagnosis was omitted from the LDAN Bill consultation, with the Scottish Government claiming that work was to be done in this area. As yet, there has been no evidence of a plan from the Scottish Government to deliver consistent assessment, diagnostic and post-diagnostic pathways and support services, although we are aware of work being undertaken by the National Autism Implementation Taskforce (NAIT) to produce a practice framework for children’s neurodevelopmental pathways.

We are also aware that NAIT have presented a proposal to SIGN for a single autism and ADHD guideline, with support from Healthcare Improvement Scotland.

We also know from research undertaken in partnership with Autistic People’s Organisations (ARGH, AMASE and SEMA) that people’s experiences of assessment, diagnosis and post-diagnostic support are frequently poor, with 62% of respondents

“After repeatedly asking how that could be, I was eventually emailed a leaflet which contained live links to some organisations’ websites.”

Anonymous response to
Diagnosis Survey

to a survey saying they did not feel adequately informed about the assessment process and 64% of respondents saying they did not feel adequately informed about support services available to them.

We therefore call for the incoming Scottish Government to introduce a national neurodevelopmental pathway guarantee, ensuring that a consistent set of diagnostic criteria are applied across Scotland.

We believe pathways should be accepting of self-referral, which has been shown to be effective in Grampian, and should take a more liberal approach as to which professionals can undertake an assessment and confirm a diagnosis.

We also believe that it is essential that good quality post-diagnostic support is available to all, regardless of age at diagnosis.



3

Improve support for autistic learners and an end to informal exclusions in education

In 2019 we produced a report, **Not Included, Not Involved, Not Engaged**, in partnership with NAS Scotland and Children In Scotland. One of our key recommendations was to end the practice of informal exclusions, where parents are asked to collect their children during the school day, when the school environment is inaccessible and unsupportive. The evidence from our National Advice Line is that this practice continues. We also know of many young autistic learners being placed on part-time timetables. Where these situations occur, young people are entitled to 'alternative arrangements' for their education yet, from our experience, many do not receive this support and are therefore further disadvantaged. A more coordinated and structured approach to alternative education delivery is required.

We believe that there needs to be a greater understanding of the needs and preferences of autistic learners in terms of communication, learning styles, and the environment that works best for them.

Teachers need to be given the support and capacity to not only develop this understanding, but also how to translate this knowledge into supportive autism-specific teaching practice to meet autistic learners' needs.

Educators in Scotland have identified this as a professional development need and the Scottish Government has previously committed to addressing this through facilitating knowledge distribution of quality practice. Yet there continues to be disparity in both the professional development opportunities and the

quality of these opportunities afforded to teachers.

Current educational approaches continue to cause emotional trauma for autistic young people and their families. Informal exclusions from school and barriers to learning within schools are symptoms of the wider issues in education, as identified by the Audit Scotland and Accounts Commission report, and we still do not have data on the true extent of their prevalence.

We believe that it is imperative that teachers are supported to develop their practice and that opportunities are provided to enable this. While there have been some welcome steps in this regard, we believe that there is more that could be done. The LDAN Bill consultation spoke of mandatory training. We believe that this would be the best approach to develop reflective autism practice within the wider education system.



Deliver a reformed social care sector where specialism is recognised, third sector providers are valued; and the workforce is appropriately rewarded

Many autistic people across Scotland rely on social care services to provide support with daily living, access to community facilities, and the right opportunities to live meaningful and happy lives on their own terms. The collapse of the National Care Service across the 2021-26 parliamentary session was a deeply disappointing development for service providers like Scottish Autism. Many stakeholders gave significant amounts of time and energy to a process which was heralded as one of the most important public sector reforms for decades, but which ended with legislation being passed with a much narrower scope.

It is critical that the next Scottish Government returns to the principles which sat behind the Independent Review of Adult Social Care, which outlined a vision of delivering a rights-based system which moved away from competitive commissioning and procurement to a more collaborative approach focused on

outcomes rather than budget limitations.

“ I spend a lot more time thinking about money and how to cut down on certain things and checking my bank balance to ensure I have enough to cover upcoming bills, groceries, even fuel to get to work. ”

Scottish Autism colleague

Response to Financial Wellbeing Survey

For this to be a reality, it is critical that the third-sector is given a much stronger voice in the discussions. Too often the discussions around accountability mechanisms and oversight focused on the relationship between local government,

national government, NHS boards and health and social care partnerships. Yet the third sector provides a significant amount of the social care support in Scotland. It is crucial that this is reflected in the future discourse.

We conducted a staff financial wellbeing survey in 2023. The findings made for incredibly sobering reading, with many colleagues making difficult financial decisions due to the persistent low-pay in the sector.

For as long as the Scottish Government sets the bar at ‘real living wage’ for the sector, in effect the minimum wage, we will continue to see people face difficult financial choices, and ultimately we will continue to lose staff to better paying roles, whether those be equivalent roles in the NHS or local authority settings, or roles outside of the social care sector.

5

End the categorisation of autism as a mental disorder within the Mental Health (Scotland) Act

Autism is a neurodevelopmental difference, not a mental health condition. That is not to say that autistic people do not experience poor mental health and require the support of mental health services, but this should be on the basis of their presentation rather than their being autistic.

While autism is not explicitly referenced in the 2003 Act, the Scottish Government is on record as stating it considers autism is covered by the term 'learning disabilities' as recommended by the Millan Committee.

This approach ignores our modern understanding of autism, but we also consider that learning disabilities should not be categorised as mental disorders either. The independent Rome Review recommended ending the categorisation of autism and learning disability as mental disorders. We believe that the ongoing review of mental health legislation must address this question during the upcoming session of parliament.

By passing the LDAN Bill, creating a neurodevelopmental pathway which provides appropriate guidance, support and signposting at all stages of the journey, the incoming Scottish Government can lay the necessary groundwork to remove this categorisation and end the iniquity faced by autistic people and people with learning disabilities who can be deprived of their liberty on the basis of their diagnosis.

“ I have spent the past two years exploring and understanding myself, navigating the benefits system, and feeling so unheard by the NHS. ”

Josh (autistic adult)

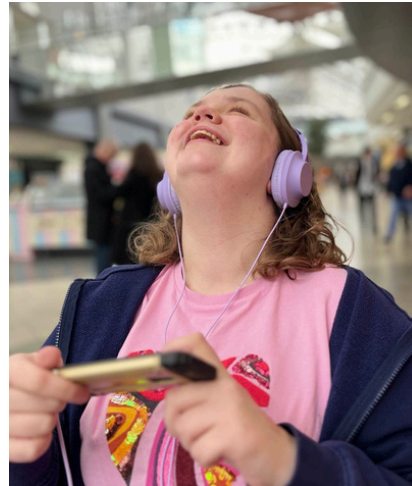


Conclusion

We believe that these priorities are deliverable and have the potential to be transformational. We consider that they would also prove to not just be affordable but would likely result in money being saved due to a reduction in the need for crisis support to be deployed, which carries significant costs in both economic and social terms.

The next Scottish Government must not shy away from delivering the change that autistic people, their families and supporters need.

We ask Scotland's politicians to rise to the challenge in the next session of parliament.





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www.scottishautism.org/seizing-the-moment

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