



The National
Autistic Society
Northern Ireland



Broken promises



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Executive summary and recommendations

The 2011 *Autism Act*, Action Plan and Strategy increased the hopes of autistic people and their families.

However, their experiences suggest that life is getting more, rather than less, difficult for autistic people, and services are failing to deliver:

- 35% of autistic adults and 46% of family members feel support for autistic adults and children has worsened in the last three years
- two-thirds said there was not enough support for parents and carers.

As a result, autistic people and their families feel their hopes for a better future have been dashed. We are asking the Northern Ireland Assembly and Government to act now to fulfil their promises:

Promises on involvement:

- ensure that the Autism Strategy and first Action Plan are fully implemented
- put in place independent scrutiny and monitoring of the Autism Strategy and Action Plan
- involve and consult autistic people, parents/ carers and the autism sector in the development of the new Autism Action Plan, its monitoring and implementation
- implement a thorough review of autism funding required across departments to address the existing funding gap, taking into account the emerging data on autism from Health and Education.

Promises on diagnosis:

- make sure the welcome new funds for diagnosis for children reach the front line – and evaluate the impact of this funding on waiting times
- report on diagnosis times and invest in diagnostic services for adults – they are just as important as those for children.

Promises on care and support:

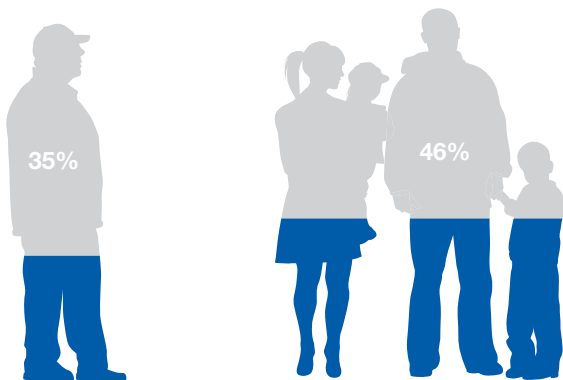
- create a new funding pool to enable the development of new services for autistic adults, children and their carers
- create a record of all unmet need that is outlined in carers' assessments and needs assessments and use it to inform the commissioning of services
- ensure that carers of autistic children and adults receive the respite they need, when they need it
- invest and expand the range of respite services in Northern Ireland for carers of autistic people.

Promises on education and employment:

- examine the data showing the type of autism-specific provision that parents would like their children to receive and invest in at least one autism-specific school in Northern Ireland so there is genuine choice within the system
- ensure that students in further education can use their Disabled Students' Allowance to access their own autism-specific support, if wanted
- undertake an independent examination of the range of support provided to autistic young people/adults to examine if it meets their needs
- ensure that autistic adults can access a range of autism-specific pre- and post-employment support that best meets their individual needs
- devise and implement an awareness raising campaign aimed at employers to increase their understanding of autism and help create real jobs for autistic adults
- ensure the Northern Ireland Assembly, government departments and associate agencies show leadership by monitoring the number of autistic people they employ and proactively examining their recruitment policies to ensure equal access.

Promises on understanding autism:

- fulfil the requirement under the *Autism Act* and secure funding to develop a public awareness campaign on autism that will promote real understanding
- require government departments and associated agencies to instigate a programme of training in serving autistic people and sign up for autism-friendly or similar awards.



35% of autistic adults and **46%** of family members feel support for autistic adults and children has **worsened** in the last three years.



Foreword by Shirelle Stewart and Arlene Cassidy

“The ***Autism Act, Strategy and Action Plan*** was a blueprint for change, but it needs to be implemented in full, with the genuine participation of autistic people and their families and a clear accountable process for overseeing the implementation.”

The passing of the ***Autism Act*** in 2011 marked a step change in political leadership on autism in Northern Ireland. The Strategy and Action Plan that was developed as a result of the Act brought autistic people, their families and the wider autism sector together. There was widespread consultation across Northern Ireland, which encompassed the whole spectrum and age range, and people felt they were being listened to after years of being ignored. The changes proposed in the Strategy offered promise.

Five years later, our charities want to know what has changed for autistic adults, children and their families and what else needs to change so that everyone gets the right support and understanding at the right time. We have found some great examples of autistic people being supported because of an individual service, charity or person. But in too many cases, people are struggling to get services and are being forced to fight for support, leading them to feel isolated, frustrated and alienated from the services they need and the communities they want to be part of.

Sadly our research suggests that far more people feel that services have got worse for autistic children and adults than feel they have got better. Only 8% of our survey respondents told us that services for children had got better, compared with 46% who felt they had got worse. For adults, even fewer, 4%, feel that services are better, whereas 35% say they have got worse.

But it's not just support that has been lacking. So has oversight and accountability. Since the publication of the Strategy and Action Plan, parents, carers, autistic adults and the autism sector have not been involved in the oversight of its implementation. This has led to frustration, disillusionment and the feeling that there is a lack of accountability.

This needs to change and the election of a new Northern Ireland Assembly provides a clear opportunity to reinvigorate all parties' commitments to improving support and understanding for autistic people and their families. The ***Autism Act, Strategy and Action Plan*** was a blueprint for change, but it needs to be implemented in full, with the genuine participation of autistic people and their families and a clear accountable process for overseeing the implementation. The Northern Ireland Executive will be developing a new action plan this year. We need the Northern Ireland Assembly to show leadership once again and make sure the necessary resources are in place to realise the promise of real change for autistic people and their families in Northern Ireland. This can't wait. We demand action now.



Shirelle Stewart
Director, **The National Autistic Society Northern Ireland**



Dr Arlene Cassidy MBE
Chief Executive, **Autism NI**





What is autism?

Autistic people see, hear and feel the world in a different way from other people. If you are autistic, you are autistic for life – autism is not an ‘illness’ and cannot be ‘cured’. Often people feel that being autistic is a fundamental aspect of their identity.

You might hear people say that autism is a spectrum condition. This means that, while all autistic people share certain difficulties, being autistic will affect them in different ways. Some autistic people also have learning disabilities and other conditions. As a result, people need different levels of support. Autistic people may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours.

It is estimated that more than 20,000 people in Northern Ireland are autistic.

About Autism NI and The National Autistic Society NI

Autism NI and The National Autistic Society NI have over 40 support groups across Northern Ireland, providing advice and support to thousands of autistic people and their families and carers every year. Both organisations deliver services and campaign for lasting positive change for people living with autism.

Timeline

2001

Autism NI started to lobby for autism to be a funding priority for government.

2006

Autism NI began the campaign for autism legislation in Northern Ireland.

2009

Minister Michael McGimpsey MLA published, in June 2009, the *Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/2009 – 2010/11*. This arose out of the independent autism review by Lord Maginnis.

The minister then commissioned the Regional Autistic Spectrum Disorder Network (RASDN) to take forward the implementation of the strategy. Both The National Autistic Society NI and Autism NI were involved with RASDN.

2011

The *Autism Act (NI) 2011* came into operation on 9 August 2011, putting autism at the forefront of the political agenda in Northern Ireland.

2011-2014

The National Autistic Society NI, Autism NI, other autism voluntary and community sector partners, parents/carers, autistic adults and representatives from all the government departments sat on the Autism Strategy project board and advised on its content. There was also widespread consultation on the Autism Strategy and Action Plan with the autism community across Northern Ireland.

2014

Launch of the Autism Strategy (2013-2020) and Action Plan (2013-2016), 14 January 2014. Statement by the Health Minister Edwin Poots.

2015

Progress Report on the implementation of the cross-departmental Autism Strategy (2013-2020) and Action Plan (2013-2016), 13 November 2015. Statement by the Health Minister Simon Hamilton.



Past promises on autism

There have been a number of initiatives to improve the quality of life of autistic children and adults as well as their families and carers (see timeline on page 9). Many of the Northern Ireland research reports from the late 1990s and early 2000s emphasised the importance of multi-disciplinary intervention strategies, co-ordinated multi-disciplinary assessment and diagnosis, training and the expansion of services. Most reports emphasised the need for strategic planning and integration as being key to success, as well as the involvement of autistic people, their families and the autism sector.

Minister McGimpsey MLA, in the foreword of the ASD Strategic Action Plan in 2009, said, “There was a clear view expressed (from the people who responded to the consultation) that there should be promotion of a more seamless, coordinated range of services for children, adolescents and adults living with ASD. The responses also underlined the need to involve individuals, families, carers, voluntary and community sector groups, and representatives from other departments and agencies, in the further development of ASD health and social care services.”¹

The Regional Autistic Spectrum Disorder Network (RASDN) was set up as a network of parents and carers, autistic people and the voluntary and statutory sector representatives who worked together to devise services that best meet the needs of autistic people and their parents and carers. A number of improvements and initiatives arose from RASDN. These included some initial and recurrent financial investment and some service improvement. Under RASDN we saw each Health and Social Care Trust appoint an ASD coordinator and teams were developed to diagnose and support children and adults. Under RASDN the children’s and adults’ care pathways were also developed and attempts were made to improve regional consistency in terms of diagnosis and service provision for both adults and children.

However, progress was slow and with an increase in those seeking a diagnosis and the need for services, Autism NI’s campaign for legislation began to gain momentum. The All Wales Autism National Strategy was groundbreaking as the first of its kind and set the tone for a cross-departmental approach. The passing of the *Autism Act* in Westminster, spearheaded by The National Autistic Society, also provided extra drive to make sure autistic people in Northern Ireland would have at least the same rights and protection as those in England. Legislation would mean there was a legal requirement for the statutory sector to provide services and support, regardless of where a family lived. Arlene Cassidy, CEO of Autism NI, stated, “Legislation is legally binding; what will be done. Strategies are what should be done.” The National Autistic Society Cymru has now garnered a lot of political support for an Act for Wales and the Autism Bill currently going through the Dáil is based on the Northern Ireland Act.

Autism Act (NI) 2011

The *Autism Act (NI) 2011*, its inter-departmental Strategy (2013-2020) and accompanying Action Plan (2013-2016), put autism at the forefront of the political agenda in Northern Ireland. The *Autism Act* came into operation on 9 August 2011. The Act is a rights-based piece of legislation which aims to ensure that autistic people have the same entitlements and opportunities as those with other disabilities. The *Autism Act*, which is the most comprehensive single disability rights-based legislation in Europe, had two main purposes.

- 1 Amendment of the *Disability Discrimination Act 1995*
- 2 Preparation of a cross-departmental Autism Strategy.

1 Department of Health, Social Care and Public Safety. (2009). *Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09 – 2010/11*. p3. Available at: www.hscboard.hscni.net/asdnetwork/Publications/DHSSPS%20ASD%20Strategic%20Action%20Plan%20June%202009%20-%20PDF%20373KB.pdf (Accessed: 26 April 2016).

The Act states that prior to implementation, the Department of Health, Social Services and Public Safety (DHSSPS) must consult with the other Northern Ireland government departments on the Strategy and compels them to co-operate on its preparation, review and implementation. Under the Act, the Health and Social Care Trusts are required to provide and share data on autism prevalence in their area.

With regards to the content of the Autism Strategy, the Act states that it must set out how the needs of autistic people are to be met through the whole of their lives and how the needs of their families and carers are to be addressed. In addition, the Autism Strategy must also set out the department's proposals for promoting an autism awareness campaign.

Cross-departmental Autism Strategy and Action Plan

In his ministerial statement at the launch of the Autism Strategy (2013-2020) and Action Plan (2013-2016) on 14 January 2014, Minister Poots MLA stated, "The successful development of the strategy and action plan can be attributed to the effective work of the multi-agency, multi-disciplinary project board, coupled with the proactive input of the autism community throughout Northern Ireland. From the very earliest stages of development, the Autism Strategy Project Board engaged with and ensured the involvement of representatives from all departments, health and social care organisations and the community and voluntary sectors".² He then clearly highlighted the need to involve autistic people and their families and carers in the implementation of the plan, "It is vital that we retain the voice of people with autism, their families and carers and they continue to be involved during implementation of the Strategy and Action Plan."³

Unfortunately, engagement ceased as soon as the Action Plan was developed. Autistic people, parents/carers and the autism sector have not been involved in overseeing the implementation or monitoring progress.

The body responsible for overseeing the implementation of the strategy is the Autism Strategy Regional Multi-Agency Implementation Team (ASRMAIT) which is comprised of departmental officials.

To end the era of broken promises and give new hope to autistic people and their families, we are calling on the Northern Ireland Assembly to fulfil its promises:

- ensure that the Autism Strategy and first Action Plan are fully implemented
- put in place independent scrutiny and monitoring of the Autism Strategy and Action Plan
- involve and fully consult autistic people, parents/carers and the autism sector in the development of the new autism action plan, its monitoring and implementation
- implement a thorough review of autism funding required across departments to address the existing funding gap, taking into account the emerging data on autism from Health and Education.

“It is vital that we retain the voice of people with autism, their families and carers and they continue to be involved during implementation of the Strategy and Action Plan.”

Minister Edwin Poots MLA, 2014

2 Minister Edwin Poots. (2014). *Ministerial Statement Autism: Strategy and Action Plan*. p1. Available at: www.niassembly.gov.uk/globalassets/documents/official-reports/plenary/2013-14/14-january-2014-revised-consolidated.pdf (Accessed: 26 April 2016).

3 Minister Edwin Poots. (2014). *Ministerial Statement Autism: Strategy and Action Plan*. p2. Available at: www.niassembly.gov.uk/globalassets/documents/official-reports/plenary/2013-14/14-january-2014-revised-consolidated.pdf (Accessed: 26 April 2016).



Promises on diagnosis

The first step to getting support is usually to be diagnosed with autism. Without a diagnosis, it is very difficult for professionals to know what support is most likely to boost people's quality of life and outcomes. The longer people wait for a diagnosis, the longer they and their families suffer without support.

Promises for children

The children's care pathway states that children should be assessed within a 13-week period to enable them to access the care and education they need. But, in fact, waiting times for assessment and diagnosis for children in Northern Ireland have spiked. According to the Health and Social Care Board's latest report (February 2016)⁴ there were 2,079 children waiting for an autism assessment in Northern Ireland, with children in the Belfast Trust waiting up to 20 months to receive a diagnosis. Of the 2,079 children currently waiting for an autism assessment in Northern Ireland, 279 have been waiting for over a year.

In our survey, we found:

- over 50% of respondents who received their formal diagnosis in the last two years had to wait between one and two years from first discussing autism with a professional, and one in five had been waiting between three and five years
- only just over one in five (22%) respondents to the survey were satisfied with the support they received after diagnosis and only 25% agreed that the information given to them after diagnosis helped them get the support that they need.

To address the challenge of waiting times, the Health and Social Care Board stated on *The Nolan Show* in February 2016 that it needed an extra £2.8 million to address the waiting times for the assessment of children in Northern Ireland suspected of being autistic.

The representative from the Board said this request had been made to the Assembly 18 months earlier.

On 14 February 2016, 18 months after the initial request and following intense lobbying from the All Party Group on Autism (APGA), Minister Simon Hamilton MLA finally announced that two million pounds would be invested in autism services across Northern Ireland. We welcome this investment – we now want to be sure that it reaches the front line and reduces waiting times to the agreed 13-week period. That's long enough for any child and their parents to wait.

“Going through the process again with a younger child at the minute and the waiting times have gone from long to ridiculous.”

“A lot of parents can't seem to get support and waiting lists take forever and depending where you live also dictates what support there is available. Parents of children, teenagers and adults should be able to access support when required and should be informed of what is available.”

“Waiting lists are longer and it's harder to get the help needed. It's actually quite soul-destroying for parents fighting for special needs children.”

⁴ Claire Crombie citing Stephen Nolan. (1 February 2016). 2,000 Northern Ireland children wait up to 20 months for autism diagnosis. *Belfast Telegraph*. Available at: www.belfasttelegraph.co.uk/news/northern-ireland/2000-northern-ireland-children-wait-up-to-20-months-for-autism-diagnosis-34412995.html. (Accessed: 26 April 2016).

Promises for adults

Many people on the autism spectrum do not receive a diagnosis until they are adults. Because autism is a developmental condition, and not a learning difficulty or mental health issue, autistic people can fall through the gaps in service provision, with neither learning disability nor mental health teams taking responsibility for their care. The *Autism Act* sought to address this issue but autistic adults are still falling through the gaps in service provision.

The Adult Autism Care pathway was produced in 2012 but funding for services for autistic adults is less than a quarter of that allocated to children's autism services. Too many adults are misdiagnosed with mental health conditions, leading to the wrong support and services being provided. This is a waste of the lives of these individuals and a waste of public money.

We believe the Northern Ireland Assembly should fulfil its promises:

- make sure the welcome new funds for diagnosis for children reach the front line – and evaluate the impact of this funding on waiting times
- report on diagnosis times and invest in diagnostic services for adults – they are just as important as those for children.

“Diagnosed as having bipolar depression at 13 and treated accordingly, only receiving a diagnosis of autism and ADHD at the age of 30. Autism and ADHD diagnosis was by an independent consultant psychiatrist as the WHSCT were unable to produce anyone within adult services with experience of autism to do so. Suspended from day-care services as staff were inadequately trained in dealing with those with autism and behaviours that challenge, without services for seven plus years.”

Carer of autistic adult



Promises on care and support

Diagnosis should open the door to support and services for autistic children, adults and their families. The type of support people need varies. It may include either home, community, residential or respite care, depending on people's needs. Autistic people who are able to live in the community may need support to develop social and communication skills or they risk being isolated and unable to cope with daily tasks. Other people will need round-the-clock care and without it can risk developing both physical and mental health problems. Families with autistic children also need support in their role as carers.

“I am so sorry to be so negative but our experience is that no one listens, no one wants to know and even when they do know they do nothing about it. They just fob us off with placating letters and excuses. It has been one long struggle and fight to get anything he needed and unfortunately it continues.”

Promises for children

Our survey of over 400 people in Northern Ireland in June 2015 found that services to support autistic children and families seem to have got worse, rather than better. Our research found that:

- only 8% of those in our survey felt that services for autistic children had improved in the last three years

- a mere 4% felt services for adults had improved in the last three years
- 46% felt services for children had got worse
- 35% of adults felt services had got worse
- 29% felt that services for children had stayed the same
- 21% felt that services for adults had stayed the same.

Waiting for services continues after diagnosis

Three quarters of parents of autistic children would like autism-specific social and leisure activities, although only one in five were able to access these activities. Two thirds of parents would like access to non-autism-specific services, with fewer than 15% receiving them. Not being able to socialise can lead to extreme isolation, for both the autistic child and their family. The *Too Much Information* campaign report⁵ recently found that 70% of family members say that they feel socially isolated. One study found that social isolation is as dangerous for physical health as smoking 15 cigarettes a day.⁶

“My son is very isolated, he has no friends to play/hang out with... He has high functioning autism... I feel I have nowhere that fits him, he does not see himself as autistic, but he isn't neurotypical either... he has no peer group that fits with him.”

5 The National Autistic Society (2016). *Too Much Information report*. London: The National Autistic Society. Available at: www.autism.org.uk/tmi (Accessed: 26 April 2016)

Diane

Diane's story is typical of the stories we hear every year from hundreds of families, having to fight a system to get basic support for herself and her children:

Diane is the mother of three children, all of whom are diagnosed with autism. Her sons are 13 and 11 and her daughter is eight. For each child, the waiting time for assessment and diagnosis increased and for her youngest it took 22 months before she was eventually diagnosed. Diane says "I thought it would have been more straightforward the third time round, but it was more protracted than ever."

After diagnosis, Diane struggled to get services for her children. "I felt I had worked my way up one really long waiting list just to hit the bottom of another. We waited 10 months for psychology services for our son, then he reached crisis point and finally we got seen. I'm now waiting eight months for services for my younger son and he still hasn't been seen. You wouldn't be expected to wait that long for other conditions but there aren't enough staff or resources, and no one works together."

Diane feels extremely frustrated with the way services are offered. "You can only be on a waiting list to access one service at a time. So you could be waiting a year for one service, then you need to start the process all over again at the bottom of a waiting list for another service. They talk about early intervention but there is no such thing as early intervention in Northern Ireland."

How can there be when it takes nearly two years for a diagnosis and there are no resources or services available?"

"You're trying to get your head around everything (the diagnosis) and dealing with a school that doesn't understand, then you need to fight for everything. I have had to fight a lot and we're still fighting for services. We're going to have to fight again for my youngest child."

This pressure to have to fight for every service has had other 'ripple effects' – Diane asked her work to be flexible because of the work she needed to do to help her children with their diagnosis, but they refused. This led to stress and anxiety that resulted in Diane needing counselling and medication. She has had to give up her work to be able to fight to get the services and support her children need.

Diane also experienced difficulties in getting the right support from education. "The statementing process is awful, especially if your child is quiet because they don't understand how much anxiety or difficulty he's having. The school is given a questionnaire to fill out but no guidance on how they are meant to fill it out. When I mentioned to a consultant about the reports professionals write, he said 'I didn't think anyone even reads these'. I felt awful – like it wasn't important at all." The one-to-one classroom assistant for one of her sons has no autism training and this causes massive worries about the help her son is getting in school.

“Three visits from early intervention and my child was then struck off the list as this was all that could be offered. Apparently we'd had our turn.”



No stopping
except
local buses

43

X50

X50



Promises for adults

Care and support for adults also seems to have fallen behind what was anticipated with the passing of the Act and Strategy. With the right support at the right time, autistic adults can live fulfilling lives. They may need care to help with basic needs, like washing and dressing, or support to plan and travel to a job they can excel in. However, over two thirds of respondents told us they didn't have enough support to meet their needs. According to our survey:

- almost half of adults (46%) have never had their needs assessed by social services
- nearly half (45%) would like help to live more independently but only 4% receive this support.

"I am extremely disappointed for my son who has Asperger syndrome. Since he never got a statement of educational needs, he's had no formal support since he turned 18. He rarely leaves the house, and is usually with me when he does. The only recourse open to him is the area mental health team and he refuses to meet with them. He suffers from general anxiety disorder and social phobia. I believe he needs counselling and/or support, but he refuses. His social worker closed his file when he was 12 against my wishes. But it was a general social worker, not affiliated with special needs, because of a lack of statement. This is where the system fails in my opinion. People like my older son fall through the cracks. He drifted through school, and wasn't entitled to any extra help, he left full-time school at 14 and wouldn't attend the part-time education services. So he was at home by the time he was 16. He went out with a few friends for a couple of years but has mostly been in the home for the last four years. A life wasted and nowhere to turn." – a parent

"It's sad to say... but I'm 47 years old and my life has been a struggle and very difficult at times and I hope that I get the help that I deserve." – Autistic adult

"Adults remain somewhat ignored. Effective services are yet to be developed. Historically, there has been under-investment – no progress can be made until it is rectified. Although there is now better awareness of autism, there remains a lack of understanding among professionals, GPs, diagnosticians, mental health workers and the general public."

Autistic adults and children should be able to access social and leisure opportunities like everyone else. Yet too often they end up isolated.

Similarly, almost three quarters (73%) of autistic adults said that they would like autism-specific social and leisure activities with only 5% receiving that support. Well over half (59%) of autistic adults who took part in our survey said that they would like non autism-specific and leisure activities compared with 7% who received them.

"Specific activity groups to meet all on the spectrum. My son is severe with challenging behaviours. He requires one-to-one support at all times and two-one when outside on occasions. He is non-verbal and has issues with hyperactivity and aggression. I have found the vast majority of groups within the voluntary sector are for more high functioning kids. These groups are unable or unwilling to meet the needs of my son and children like them because their autism may present as more complex than the average autistic person. Therefore he is isolated even within the autism community."

"I don't go out and nobody has told me of anything. My mother tries to encourage me to go out, but I feel I can't. I don't know what would make me want to go out. I feel safe at home."

Care and support for family members

Fighting for services and investing your own time in supporting an autistic family member can put a real strain on parents and family carers. Carers save the Northern Ireland economy over £4.4 billion a year – more than the annual NHS spend in Northern Ireland.⁷ Many carers of autistic children and adults have to give up work to care for their loved one. They need support to continue to do this, without their own physical and mental health worsening. Short respite breaks can make a huge difference to families' ability to continue caring and can improve their own health. A report by Rosie Burrows, *Is anyone listening*⁸, found that parents of autistic children experience a continuum of stress:

- over 90% of parents experience significant anxiety
- 57% report acute anxiety and panic states
- nearly 65% of those interviewed reported illness linked to caring for an autistic loved one
- over 50% of mothers are currently taking medication as a way of coping with stress levels.

Parents and carers of autistic people paint a very clear picture of the difficulties they face in getting support for themselves and their frustration at having to fight for services and support for those they care for. A carer's assessment is a way of identifying a carer's needs. It looks at the person's role as a carer: how being a carer affects them, how much caring an individual can realistically do (while still allowing them to be involved in other activities outside of caring), and any help they may need.

The *Carers and Direct Payments Act (2002)* places an obligation on Health and Social Care Trusts to inform carers about their right to an assessment. According to our survey, 65% of carers had never received a carer's assessment. Of the third who had received an assessment, two thirds felt that they had not received support as a result of the assessment.

Our survey told us that:

- 73% of parents/carers who responded said they felt isolated
- 52% stated that caring had negatively impacted on their finances
- over half of carers, 54%, wanted more respite
- when we asked how services and support for families and carers of autistic people had changed in the last three years, fewer than 3% of respondents said that they had improved, while more than two thirds responded that they had got worse or stayed the same
- 88% felt there was not enough support for parents and carers of autistic people from social services.

"We have been begging for help with our son's behaviour problems for 16/17 years, he can be very aggressive and violent, kicking and hitting at us and furniture. We frequently have to leave for our own safety. No one would listen, until it was witnessed by a therapist three years ago. He has tried to provide some intervention, he used to have a team working with him but he has been reduced to working on his own for the past two years. Our trust simply does not care."

"I feel bereft of meaningful support for the day-to-day practicalities regarding assessments and progressing."

"Cuts, cuts and more cuts."

"I have never received any help as my son is not considered disabled enough."



⁷ Carers NI. *Facts and figures*. Available at: <http://www.carersuk.org/northernireland/news-ni/facts-and-figures>. (Accessed: 26 April 2016).

⁸ Autism NI (2010). *Is anyone listening?* Belfast: Autism NI. Available at: <http://www.autismni.org/is-anyone-listening.html>



Caring for a sibling

“My mother was my 41-year-old brother’s lifetime carer. He is non-verbal and has a severe learning disability. Sadly, our mother passed away very suddenly a few months ago. The social worker asked us if we were prepared to care for our brother and without question, it was a decision we all agreed to. However, the lack of support from social services still shocks me to the core.

There were huge difficulties with this transition, we had to move house to accommodate an extra adult living with us, my husband had to give up work to attend to my brother’s personal needs and not to mention his very challenging behaviours at having to cope with his grief and loss of his home.

Despite several weekly phone calls to the social worker for support and help, he refused to return our calls, no consideration given at all to our own son with ASD. By chance, we mentioned this at our local parent support group meeting and with the help of The National Autistic Society we finally got the trust to acknowledge we needed support and help with this life-changing transition. If it wasn’t for The National Autistic Society, we would never have heard of direct payments or that respite was an option for us, nor would we have been aware that our brother and we as a family were entitled to benefits. Things are working out now but I dread to think of what would have happened if we hadn’t gone to the support meeting, I don’t think we could have continued to care for my brother.”

“From my experience as a carer of two severely autistic brothers, not enough support is being made available to families with autistic children. Though daytime respite may be widely available, availability of overnight stays away from home for those who have severe autism must be improved. Support could be improved much more if the process for overnight stays wasn’t so long and there were more facilities.”

Promises on funding for care and support

So why haven’t these promises on care and support been kept? Funding is part of the problem. In the HSCNI’s Commissioning Strategy⁹, a number of areas are highlighted as being underfunded. These include learning disability services, mental health services and family and childcare services, all of which are accessed and needed by autistic people who have additional needs. They state that “The funding position in 2015/16 will impact on the ability of commissioners to take forward a range of services relating to the need for assessment of children for autism spectrum disorders... and treatment/support services for children and their families.”¹⁰

In the year 2015/16, the total amount allocated for autism services across the five Health and Social Care Trusts was £4.8 million pounds, on average £900,000 per Trust area.¹¹

The table below shows the recurrent funding allocation to HSC Trusts for autism services in 2015/16. HSC Trusts were also provided with an additional £50k each in 2015/16 to help address waiting lists for diagnosis. The DHSSPS seems to be having to crisis-manage autism services rather than having any long-term or strategic plans for the commissioning of services.

There are particular gaps in funding for adult support. While the Northern Trust area spends the largest proportion of its budget on adult services, 26%, on average, only one out of every five pounds allocated for services was spent on adult services within each of the Trust areas.

It seems that the outcomes of the Autism Strategy and Action Plan, even though they are the responsibility of all government departments, have no funding attached to them. Other government departments are on the whole taking a pan-disability approach while not monitoring whether or not their approach is effective in meeting the needs of autistic people. While the *Autism Act* legislated for a cross-departmental strategy, the responsibility for providing services has fallen on the whole to the DHSSPS and DENI alone.

Autism is a lifelong disability that impacts on all areas of an autistic person's life from the provision of services for health and education to further education, training, employment, housing, social and leisure opportunities. It is everyone's responsibility and the Northern Ireland Assembly needs to ensure that funding for services for autistic people comes from all government departments.

To help all autistic children and adults get the care and support they need, we are calling on the new Assembly and Government to:

- create a new funding pool to enable the development of new services outlined in the new Autism Action Plan
- ensure the carers of autistic children and adults receive the respite they need, when they need it
- invest in and expand the range of respite services in Northern Ireland for carers of autistic people.

2015/16	Children	Adults	Total
Belfast Trust	£743,671	£149,068	£892,739
Northern Trust	£600,997	£209,754	£810,751
South Eastern Trust	£507,391	£142,445	£649,836
Southern Trust	£1,056,322	£183,460	£1,239,782
Western Trust	£766,848	£189,914	£956,762
Total	£3,675,229	£874,641	£4,549,870

9 Health and Social Care NI (2015). *Commissioning Plan 2015/16*. Health and Social Care and Public Health Agency. Available at: www.hscboard.hscni.net/publications/Commissioning%20Plans/440%20Commissioning%20Plan%202015-16%20PDF%204MB.PDF. (Accessed: 26 April 2016).

10 Health and Social Care NI (2015). *Commissioning Plan 2015/16*. Health and Social Care and Public Health Agency, p83. Available at: www.hscboard.hscni.net/publications/Commissioning%20Plans/440%20Commissioning%20Plan%202015-16%20PDF%204MB.PDF. (Accessed: 26 April 2016).

11 Question AQW 40024/11-15. Available at: <http://aims.niassembly.gov.uk/questions/searchresults.aspx?qf=0&asb=0&tbn=0&anb=0&abp=0&sp=1&qfv=1&asbv=0&tbnv=1&anbv=0&abpv=0&spv=18&ss=2ua7i1takRpUg9dgyYR5AQ==&tm=2&per=1&sus=1&qs=1&ans=1&it=1&fd=&td=&pm=0&asbt=All Members&anbt=All Ministers&abpt=All Parties&spt=2015-2016>. (Accessed: 26 April 2016).

Promises on education and employment

Promises at school

School days should be a time when children are safe, happy and confident and able to make the most of their abilities and talents. Parents of autistic children want an education system that is ambitious for their children and gives their children similar opportunities to others. They want a system that understands and supports their child's needs, allowing their child to enjoy good emotional and mental health and preparing them for life. Parents want to choose where their child is educated and to ensure the right support. However, that support is not always appropriate or easy to obtain.

“My daughter needs more help at school but can't get it.”



Encouragingly, the majority of parents (two thirds) who responded to our survey said they were satisfied with the education placement that their child was receiving. However, a significant minority (26%) of parents were dissatisfied.

Many parents told us that getting support in school was not easy and they had to fight to get the help their child needed. The *A* for Autism* report (2012) found that 52% of parents who responded had to wait over a year from when concerns were first raised about their child to actually getting appropriate support. Twenty-two per cent had waited over two years.¹²

Almost two thirds (65%) of those who expressed dissatisfaction with their present placement would like their child educated either in an autism-specific unit attached to a mainstream school or an autism-specific school.

The majority of children (73%) were attending a mainstream school. When we asked parents what type of provision they would choose, if they had a choice:

- almost a quarter (24%) would choose mainstream provision
- the same amount (24%) would choose an autism-specific unit attached to a mainstream school
- almost one in three (30%) would choose an autism-specific school.

Our survey suggests that parents want a choice of provision for their autistic child. However in Northern Ireland there are a limited number of autism-specific units and no autism-specific schools – every other nation of the UK has at least one autism-specific school.

“My son is due to transition from an ASD unit within a mainstream school, there is no secondary school with a unit in Belfast, there is no info regarding secondary schools’ autism pastoral support and training and no way of comparing schools based on objective evidence of support. Further I have no idea what, if any, support my son can expect from the education board on transfer from a high support unit to mainstream secondary – if he has sufficient support he will be likely to succeed, if not he will be likely to suffer high anxiety and risk being out of school.”

Many parents also cited the need for teachers and classroom assistants to be properly trained in autism.

¹² The National Autistic Society Northern Ireland (2012). *A* for Autism*. Belfast: The National Autistic Society

“School has excluded my son many times. He is left in a unit and not helped, even though he has a one-to-one. He is left to sleep.”



The Department of Education in Northern Ireland has invested substantial resources into autism training materials and a programme of support from Middletown Autism Centre. While this is extremely welcome, it is not mandatory for classroom assistants or teachers to undertake this and they must use their own time to learn the basics about autism. Given that every teacher will teach multiple autistic children during their careers, this puts these children at risk of being taught by teachers who have not chosen to educate themselves in their own time.

Steven

Steven is five years old and is diagnosed with autism and a specific language impairment. Initially the statutory assessment for a statement of special educational needs was denied by the Education Board as ‘one report from an educational psychologist said Steven could cope with no educational support’. This contradicted all the other professional reports which showed he would need significant support.

Steven’s parents met with the board to get the assessment reviewed as he was due to be placed in a mainstream primary school with no support. The mainstream school that Steven had been allocated a placement in had stated that they would not be able to meet his complex needs and would not be able to accept him in school.

This caused huge stress, with the parents taking the lead and contacting all relevant organisations to try to get their child an appropriate placement with the right level of support.

By the start of term it was still stated that Steven would be placed in the mainstream school. His parents then made the decision to keep him at home as they felt that sending him into the mainstream school placement would have been

detrimental and a really stressful first experience of school for their child. Steven was at home for three months before the statement was finally completed and a placement was found at a specialist speech and language unit.

Steven now has an appropriate placement and is progressing well at school, although there are still some difficulties in relation to the unstructured times such as break and lunch.

His mother said, “The stress was horrendous. We had to fight with the Education Board every step of the way. It is the one time you need the system to work; you have just found out that your child has learning difficulties and you need support, but instead you have to fight for absolutely everything by yourself.”

The family also have a three-year-old daughter who is going through the process of a private diagnosis. They have chosen to pay for a private diagnosis as they are extremely anxious about ensuring that her school placement is appropriate and organised in time. They have very little confidence in the system of diagnosis and educational assessment and are trying to pre-empt any difficulties they may face.

Promises on transition from school

Change is difficult for everyone on the autism spectrum, so moving from a settled school place to adulthood can be very difficult and needs careful planning and communication. That's why good practice dictates that all children who have a statement of special educational needs, including autism, should have a transition plan. This should set out future plans and be put together following the annual review after the child's 14th birthday. It is a very important plan as it outlines a young person's wishes for all aspects of life from education to housing, employment, transport and health. The plan should include input from support workers, teachers, doctors, educational psychologists, parents and the child themselves. It is there to highlight areas where support and services may or may not be needed in the future. It also allows for smooth transitioning from the final school years into adult life and the change of services provided. A successful transition plan should involve everyone in a young person's circle of support. Planning should be person-centred, focusing on what the autistic person wants for their future and what matters to them.

There is no requirement for a transition plan to be prepared for children who do not have a statement. However, there is guidance which the Education Authority (EA) and schools must take into account, which states that the EA and child's school may wish to prepare a transition plan and offer help and guidance to pupils with special educational needs who are likely to need some support when they move to further education or training, such as school/college link courses or work placements.

However parents have told us that they experience a number of problems with transition planning. There is a lack of choice with regards to what a young person transitions to. Although on paper there are a number of available options, many young people do not fit the criteria for the programmes of support or services on offer. Those young people without a statement often have no support in accessing college, employment or day opportunities.

Many young people may not have needed to use services when they were being supported in the school system. However, when they leave the educational system, their need to access these services changes. To get access, they must go back to their GP for a referral to adult services. This is not arranged automatically through transition planning. Young people and families can feel they are moving from a safe environment to a vacuum where they have to cope on their own.

“There is very little continuous support for children and their families... No one seems to care... unless you keep shouting to be heard... I'm a single parent and have resigned myself to the fact that it's up to me to help my 16-year-old son cope with life.”





Rois-Eireann

Rois-Eireann is 18 and lives with her family in Fermanagh. She has a diagnosis of autism and a severe learning disability. Rois-Eireann is leaving school this year but has no transition plan in place despite this being a legal requirement.

A transition meeting was held in September, but her mother, Caroline, was not informed the meeting was to do with her transition, nor was she told who would be in attendance. Attendees included a social worker who had never met Rois-Eireann or Caroline; a transition officer from Jobs and Benefits, who stated she had nothing to offer the meeting; an education transition officer who was there to say Rois-Eireann's statement ended when she left special education and to give her a form to apply for reduced rate community transport as she was no longer entitled to transport if she was continuing her education at local college or FE; and finally a representative from the local day centre, who emphasised the need to make a decision as numbers were high and Rois-Eireann was in danger of missing the entry deadline.

Caroline is struggling to find a suitable post-19 placement for Rois-Eireann. Her daughter is deemed not complex enough for a day centre but is too vulnerable to travel to college on her own. Caroline has met with many agencies to examine programmes and post-19 options. This has led to a lot of disappointment as Rois-Eireann does not fulfil the criteria of these programmes.

In Caroline's search, she has found there are a number of courses and programmes available in her local area, but these places are often not being filled because they are not designed to meet the needs of the majority of autistic young people leaving special education. Caroline says "There is a real need to monitor and measure the outcomes of these programmes which all offer the same courses and skills to a very small number of people and I am not convinced of the success rate."

Peter

Peter is an 18-year-old man who lives with his family. He has attended a school for young people with a severe learning disability all of his life and is due to leave in June 2017.

In preparation for leaving and transition from the children with disabilities team into the adult learning disability team, the local Health and Social Care Trust felt that a number of assessments needed to be completed. These included an IQ assessment, social functioning and an occupational therapy assessment to identify his abilities and areas that may require support.

Peter scored above the IQ level needed to access the learning disability service. In terms of his level of functioning he is in the "extremely low level". Peter cannot read, tie his shoe laces, nor manage money and although he can bathe independently, he still requires supervision.

He is seen as extremely vulnerable. However, because his IQ is above 70, which is the cut off for learning disability, Peter cannot access a service from this team. He was referred to the ASD team within the trust. However the ASD team has said, in writing to the family, that it is clear that Peter requires a level of support beyond that which autism services can provide and that they do not have access to day opportunities or social opportunities appropriate to Peter's needs and therefore are not in a position to accept the referral.

Peter is leaving school in June 2017, but he has no service because he falls between the gaps in service provision and is being denied an appropriate service because of his IQ. His respite services have already been removed, and Peter is unable to process this huge change, resulting in increased challenging behaviours.

Further education and employment support

Autistic people can make effective and highly valued employees. As is the case with all employees, it is important to match the person's particular skills to the requirements of the post. Autistic people are often very focused and have considerable skills in specific areas. Some of these transferable skills include attention to detail, a methodical approach, strong research skills, good long-term memory and excellent record-keeping. Why then are autistic adults not accessing employment? The UK-wide research for the *Don't write me off* campaign¹³ found that only 15% of adults are in full-time employment and 9% are in part-time employment despite the fact that 79% of autistic adults on out-of-work benefits say they would like to work. In 2010, 26% of autistic graduates were unemployed six months after leaving university, compared with 12% of other disabled graduates and 9% of non-disabled graduates.¹⁴ Our survey in Northern Ireland revealed that:

- just over half the respondents said that they would like to have employment support, with only 6% saying that they received it.

Autistic adults also raised the issue of support in further education.

"I attend university and they only have generic support for disabilities, with nothing that would actually be useful in supporting me in the difficulties I have because of autism. For example, they offer note takers and mental health counsellors, but they have no interest in helping me approach lecturers about making their lectures more accessible for me. I have had lecturers start playing videos very loudly in the middle of their presentations with the only warning being 'now we'll watch a video'. If they warned me ahead of the lecture I could be prepared and maybe bring earplugs or something with me. When things like this happen, I usually have to leave the lecture theatre and miss the rest of the lecture, but the disability services don't really care. There is also no support with me getting public transport (such as being eligible for the disability pass – autism isn't eligible) despite the fact I can't drive because of my autism and my sensory processing being too slow."

“[We need]... specialised support that focuses on the needs of each individual – particularly in education, employment and social skills. More help and support in terms of finance would also be beneficial.”

So that all autistic children and adults can fulfil their potential in education and employment, we are calling on the new Assembly and Government to:

- examine the data with regards to the type of autism-specific provision that parents would like their child to receive and invest in at least one autism-specific school in Northern Ireland so there is genuine choice within the system
- ensure that students in further education can use their Disabled Students' Allowance to access their own autism-specific support if wanted
- undertake an independent examination of the range of support provided to autistic young people/adults to examine if it meets their needs
- ensure that autistic adults can access a range of autism-specific pre and post- employment support that best meets their individual needs
- devise and implement an awareness-raising campaign aimed at employers to increase their understanding of autism and help create real jobs for autistic adults
- ensure the Northern Ireland Assembly, government departments, and associate agencies show leadership by monitoring the number of autistic people they employ and proactively examining their recruitment policies to ensure equal access.

13 The National Autistic Society. (2009). *Don't write me off*. London: The National Autistic Society

14 AGCAS Disability Task Group. (2012). *What Happens Next? A report on the First Destinations of 2009/10 Disabled Graduates*. Available at: <http://www.agcas.org.uk/assets/download?file=3992&parent=419>. (Accessed: 26 April 2016).



Promises on public understanding of autism

Living a good quality life means being able to participate in your community and use public facilities like parks, cinemas and restaurants. But a lack of public understanding of autism and how it affects autistic people's behaviour too often restricts autistic people's ability to go out in public.

According to the *Too Much Information* campaign, 84% of autistic people say that the public's reaction makes them more anxious and only 16% of autistic people and their families think that the public understand autism in any meaningful way.¹⁵ Parents reported that their autistic children are labelled as naughty (75%), strange (75%) or funny (71%). Similarly, autistic adults think they are most often judged to be strange (84%), shy (70%), or anti-social (69%). Most typically people stare, tut or actively avoid them. When having a meltdown, already an extremely distressing – often embarrassing – situation for autistic people and their families, people's negative responses make it much harder to deal with. This leads to isolation, with half of autistic people and families saying that they sometimes or often feel unable to leave their homes due to their fears about the public's reactions.

In the Autism Strategy and Action Plan there was provision for the commissioning and planning of a public awareness campaign. However it was reported in the Autism Progress Report that the public awareness advertising campaign was cancelled due to financial pressures. "Specific examples of awareness raising initiatives were to be created via a public awareness advertising campaign."¹⁶ This has since been downgraded to an annual "no cost awareness initiatives and unpaid publicity particularly events focused on autism awareness month each year."

On 21 October 2015, correspondence from Richard Pengelley (Permanent Secretary of the Department of Health, Social Services and Public Safety) to Kieran McCarthy MLA stated that the proposals for an awareness campaign were prepared "however due to the percentage of awareness of autism in Northern Ireland as advised in local and national research (NAS, 2009, Dillenger et al 2013) suggesting that 80-90% of the NI population is aware of autism and about 50% of the NI residents know someone with autism personally, and in light of financial pressures it was decided not to pursue a campaign at this stage."

It is true that most of the public have heard of autism. In 2015 a UK-wide YouGov poll found that over 99.5% of people in the UK knew the term. But the evidence suggests that there is a huge difference between knowing the term 'autism' and really understanding what it means so that you behave with kindness and empathy to autistic people and their families using public spaces.

“I would say to people who stare and make fun of Malachy when we are out, that my son and his family have enough on our plate trying to access suitable activities and giving him enjoyable experiences without having to endure imitations of a child with special needs who is doing nothing but trying to enjoy life.”

15 The National Autistic Society (2016). *Too Much Information*. p7. London: The National Autistic Society. Available at: <http://www.autism.org.uk/get-involved/tmi/about/report>.

16 Department of Health, Social Services and Public Safety. (2015). *The Autism Strategy (2013-2020) and Action Plan (2013-2016) Progress Report*. point 3.5 p6. Available at: <https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/autism-strategy-progress-report-2015.pdf> (Accessed: 26 April 2016).

Malachy

Malachy is a ten-year-old boy who is on the autism spectrum, has a severe learning disability and does not have speech. He is extremely active and agile and always wants to be out doing activities or going on excursions but needs constant one-to-one supervision. Most nights after work, Mark, Malachy's dad, will take him out to visit a shop or go to the park.

Recently, Mark was changing Malachy in a cubicle at a new service station beside Lisburn. While getting changed Malachy was humming and stimming to address sensory issues given that he has no speech. Mark clearly heard people outside imitating the noises Malachy was making, which was hurtful in itself as anyone who heard the noises would have known they came from a child. Upon leaving the cubicle, the people who were making fun of Malachy and his noises were three adults in their late twenties. One had a youth worker hoodie on.

"I would say to these people and others who stare and make fun of Malachy when we are out, that my son and his family have enough on our plate trying to access suitable activities and giving him enjoyable experiences without having to endure imitations of a child with special needs who is doing nothing but trying to enjoy life."

Another occasion which proved very upsetting to Malachy's parents was when two carers took Malachy on a train journey to Bangor – he loves the motion and experience of train journeys. As they travelled, they ended up sharing a table of four. Malachy was again humming and stimming as he travelled and looked out the window. He accidentally kicked the man sitting across from him in his excitement, and the man said to Malachy, 'will you stop kicking me'. One of the carers apologised and explained that Malachy could not talk and he had severe autism, at which point the man sitting next to them said, 'well you may like the way he gets on but I don't'. This was overheard by another lady on the train who very kindly offered the carers and Malachy another place to sit.

As Malachy gets older his world is shrinking. When he was younger, having a meltdown was not subject to the same scrutiny but now he is bigger and if he cries, drops to the ground or flaps and hums in public, he attracts a lot of attention and comments. Malachy struggles to understand the world around him and can become very upset if his routine is changed or he does not understand what is happening. His parents realise that people may struggle to understand Malachy's behaviour and may not know he is on the autism spectrum but they want people to understand their son's distress and rather than judge, perhaps offer to help as the lady on the train did.

"The fact is that Malachy needs to be out and about, he needs to experience activities which he enjoys. We attempt as far as possible to shield our son and ourselves from negative attitudes displayed by some members of the public – however his happiness is more important to our family than any of their opinions and judgements and we will continue to bring him out, even if it is a 7am visit to a park on a Saturday and Sunday, or when the shop opens at 9am. This is the constant balancing act which families who have children like Malachy have to conduct when leaving the house, therefore consideration, understanding and a friendly smile from members of the public is really appreciated compared to the negative comments and dirty looks fired by people who don't understand."

"Being Malachy's parent can be a role which can leave you socially isolated. You might be going to a park on Boxing Day in the pouring rain with no one else in sight, in the early mornings before anyone else is up or other people with children will be there. However, being Malachy's parent is rewarding and we love our son dearly. He is entitled to the same happiness and fun that all children are, it is just that much more thought, effort and attention has to go into identifying where and when we can go to places so Malachy can enjoy himself but also so we do not have to experience the added pressure of judgement by members of the public."

Both of our charities have devised award systems. The National Autistic Society's Autism Friendly Award (previously the Autism Access Award) and Autism NI's Autism Impact Award encourage public spaces to be welcoming to autistic people and their families. The Northern Ireland Assembly has shown its commitment to improving access to public spaces by being the first public building to sign up for The National Autistic Society's Autism Friendly Award.

This was a very welcome step and all other national Parliaments have now followed the Assembly's lead. However, autistic people and their families need to access other public spaces: cinemas, shops, cafés, playgroups and all the other places that everyone else takes for granted. The iconic Titanic Belfast and George Best City airport are committed to becoming Autism Impact champions through Autism NI's scheme.

The Northern Ireland Assembly should take a lead on this by ensuring more public facilities are accessible to autistic people and encourage local government to make leisure centres and other locally commissioned services open to all.

To address this gap in public understanding and allow all autistic people and families to leave their homes and participate in their communities, the Northern Ireland Assembly needs to:

- fulfil the requirement under the Autism Act and secure funding to develop a public awareness campaign on autism that will promote real understanding
- require government departments and associated agencies to instigate a programme of training in serving autistic customers and sign up for autism friendly or similar awards.

Conclusion

Giving people hope again

The *Autism Act* and Strategy gave autistic people and their families enormous hope in what their future lives could be like. That hope has now disappeared as the promises of the Strategy have not been fulfilled. But we now have an enormous opportunity to give them hope again that they can have a good quality of life, getting opportunities for education, employment and community participation as well as securing essential support from health and care services.

It is possible to deliver a better quality of life for autistic people and families. Autistic adults and parents/carers have shared their experiences of what life is like for them in Northern Ireland at this time. To ensure that society accepts and understands autism and provides real opportunities for autistic people to meet their potential and lead fulfilling lives, the Northern Ireland Assembly needs to act now to fulfil its promises.

Acknowledgements

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This report was written by Shirelle Stewart.

Report methodology

The research for this report was carried out over a four-week period between 28 May 2015 and 26 June 2015.

The National Autistic Society Northern Ireland designed a survey which elicited largely quantitative responses and offered the opportunity for lengthier qualitative responses to selected questions. The aim was to find out more about the experiences, attitudes and opinions of autistic children and adults and their families and carers about support and services in Northern Ireland.

The questionnaire was advertised on The National Autistic Society website, to members, and through social networking websites, which were further shared to expand the responses to non-members of The National Autistic Society NI.

A total of 425 people responded to the survey. The vast majority of responses (82%) were from a parent or carer of an autistic person. Over four-fifths (84%) of the responses related to a child or children under the age of 17.

The National Autistic Society commissioned Breathe Research to run focus groups and YouGov and nfpSynergy to carry out a series of surveys which informed the *Too Much Information* (UK-wide) campaign report. The charity's online survey about public understanding between May and July 2015 had 7,532 respondents. Some of the results have been included in this report.

The names of some of the case studies in this report have been changed to preserve anonymity and we have used stock photography.

About The National Autistic Society

We are the UK's leading autism charity. Since we began over 50 years ago, we have been pioneering new ways to support people and understand autism. We continue to learn every day from the children and adults we support in our schools and care services.

Based on our experience, and with support from our members, donors and volunteers, we provide life-changing information and advice to millions of autistic people, families and friends so that more people can make informed decisions about their lives. And we support professionals, politicians and the public to understand autism better so that more autistic people of all ages can be understood, supported and appreciated for who they are.

Until everyone understands.

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About Autism NI

Autism NI is Northern Ireland's autism charity and was formed to promote positive collaboration between parents, professionals and individuals with autism to address the need for appropriate services.

This partnership ethos extends to the charity's promotion of a multi disciplinary, cross agency response to issues such as assessment, diagnosis and early intervention. The charity's mission to support parents and individuals with an autistic spectrum disorder is core to its work and is based on individualised assessed need. The charity is committed to promoting best practice, accessible to all irrespective of family circumstances.

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