



The National
Autistic Society
Cymru

Cymdeithas
Genedlaethol
Awtistiaeth
Cymru



Act Now

An Autism Act for Wales



Until everyone understands

Nes bydd pawb yn deall

CONTENTS

Foreword from Mark Lever, Chief Executive, The National Autistic Society 03

Introduction 04

05



**Diagnosis and
post-diagnosis
support**

06



Education

07



**Support
for adults**

08



**Support
for carers**

Act Now for Autism 09

About autism 10

About NAS Cymru 10

Acknowledgements

Thanks to all those who responded to our survey.

Their honesty and willingness to share part of their stories, how they cope with daily life and what improvements they'd like to see has better informed us as to why we need an Autism Act for Wales.

Thanks also to National Autistic Society colleagues, particularly Jane Harris, Sarah Lambert, Tim Nicholls, Tom Madders, Ian Dale, Samuel Cropton, Heidi Aho and Suzanne Westbury. Very special thanks to Mat Mathias and Samuel Stone.

This report was written by Meleri Thomas, External Affairs Manager, NAS Cymru.

Report methodology

This report is based on 668 responses to an online survey held between May and June 2015. The respondents were autistic people living in Wales, or where they were unable to participate, their parents and carers.

66

In the summer of 2015, The National Autistic Society Cymru (NAS Cymru) carried out an online national survey to find out what matters to people living with autism every single day. It sought to find out the views, experiences and priorities of autistic people and their parents or carers.



It builds on the work of our *The life we choose* report published in 2011, which found that since the introduction of the Welsh Government's autism strategy in 2008, some progress had been made but overall provision was patchy and there were gaps in services and in support.

In compiling this report, we came across great examples of autistic people being supported and having their needs met because of a specific service, charity or individual person. However, there were far too many examples of a lack of support available. In many cases people were struggling to cope and forced to fight for support, leading to them feeling isolated and frustrated.

In the words of one parent: "I find that it's people on the ground – local people, parents, ordinary workers, who are working really hard for autism and making the difference. They are working against a system that is letting them down."

In 2016, the people of Wales will vote for a new Assembly that will take us into the 2020s. It's time to Act Now for Autism and be ambitious, bold and clear about our shared aspirations for autistic people and their families in Wales to ensure they are given the opportunities to meet their potential in the same way as everyone else.

There is a real public appetite for a new law. Nearly 90% of people who responded to our survey said that specific autism legislation is needed in Wales, along similar lines to what already exists in England and Northern Ireland.

This report presents the need for an Autism Act – a piece of legislation that protects and promotes the rights of autistic people in Wales, their families and carers. It's a snapshot of what you told us mattered to you and sets out what needs to change. It's a message from autistic people and their families in Wales to politicians in Wales to Act Now for Autism.

99

A handwritten signature in black ink that reads "Mark Lever". Below the signature is a long, horizontal, slightly wavy line.

Mark Lever, Chief Executive
The National Autistic Society



In 2008, the Welsh Government led the way, as it became the first of the UK nations to publish a strategy for improving services and support for autistic people and their families.

Eight years on and despite the progress made, the needs of autistic people are still being overlooked at a local level.

Families and adults on the spectrum report having to wait years for a diagnosis. Local authorities don't know how many autistic people are in their area and so aren't planning appropriately for the support they need. Professionals aren't able to support people on the spectrum properly, as they lack training and understanding.

It has become increasingly clear that decisive action from the Government is needed. A new strategy will not be enough to deliver the shift

at a local level that is needed. Now that Welsh Government can make its own legislation, it should take this opportunity to show leadership on autism and legislate to make it much clearer how services and support should be provided to those on the autism spectrum.

The legislation we propose simply expands upon current duties. It does not seek to create significant additional burdens on local authorities and their partners. Indeed if implemented properly, there are potentially significant cost savings to the public purse.

We recommend that an Autism Act for Wales:

- 1** puts a duty on health boards to ensure that there is a clear pathway to diagnosis of autism in every area
- 2** puts a duty on local authorities to record the numbers of autistic children and adults in their area to inform planning processes
- 3** every local area uses this data, alongside consultation with local people on the spectrum and their families to develop a plan on how they will meet the needs of the local autistic population
- 4** makes sure that this data is regularly reviewed and shared between children's and adult services to ensure smooth transitions for autistic young people
- 5** ensures statutory guidance is developed to set out which professionals need what levels of training to ensure that autistic children and adults are supported by professionals who understand them
- 6** makes clear that autistic children and adults shouldn't be turned away from accessing public services because they're seen as 'too able' and their IQ 'too high'
- 7** is regularly reviewed and monitored to make sure clear progress is being made.



For autistic people, getting a diagnosis of autism is key.

It can help them and their families and carers understand why they experience difficulties. It makes it easier to make sense of the world around them, and often allows people to access services and support. In our survey, 70% of those who responded said they felt relieved to get a diagnosis.

The National Institute for Health and Clinical Excellence (NICE) has produced guidelines on diagnosing autism for both children and adults. The guidelines on 'Recognition, referral and diagnosis of children and young people on the autism spectrum' say that the diagnosis assessment should be done 'within three months of a referral'.

However, our survey shows that:

- Some six out of ten people who responded waited more than a year for a diagnosis. Almost a third (32%) waited more than two years for a diagnosis.
- Nearly two thirds (63%) of respondents said the process of getting a diagnosis took too long and 56% said the process was stressful.
- Once they had a diagnosis, only one in five (21%) said that they were satisfied that the information given to them afterwards helped them to get the support they needed.

The Welsh Government has also recognised the need to address the waiting times for a diagnosis of autism. In 2015, it established a Task and Finish Group to secure improvements in diagnosis services for both children and adults. We await the Group's recommendations in reducing waiting times and making the process of getting a diagnosis of autism easier.

What matters to you:

“ The diagnosis process takes far too long, communication between departments needs to be radically improved, more needs to be done to provide support and education post-diagnosis and to signpost people to services and additional learning and training opportunities regarding autism. ”

“ My son was not diagnosed with Asperger syndrome until he was 16 years old. I had the diagnosis and that was that. No help or advice was given. ”

An Autism Act for Wales

We recommend that an Autism Act for Wales be introduced in the next Assembly term.

We propose that an Autism Act could include:

- putting a duty on every health board to make sure there is a clear pathway to diagnosis in every area for both children and adults
- ensuring that staff across health and care are better trained in autism.

A strategy and guidelines alone have been insufficient to make this happen. Legislation would make sure that autism diagnosis is prioritised locally. It would help make clearer to individuals and families what they should be able to expect from their local services.



Parents of autistic children tell us they want an education system that gives their children the same opportunities as other children.

They want an education system that understands their child's needs, ensures their child is supported to achieve, but also helps them to develop social, emotional and life skills.

Autistic children and young people may need extra help in the education system – as well as at times of transition, when they move from one education setting to another, to make sure they can access this rounded education.

More than two thirds (69%) of those we surveyed said that their children attended mainstream education, with 17% of pupils attending specialist provision.

And four fifths of those who responded identified as receiving additional support at school because of their autism, through School Action, School Action Plus or a Statement.¹

The survey shows that:

- Only two children in five (39%) whose parent responded are receiving all the support and provisions outlined in their statement or education plan.
- Children in our survey are not getting enough of the particular types of support they need. Fewer than one in five (19%) of parents who responded felt their child received sufficient occupational therapy and only 36% felt they were receiving sufficient speech and language therapy.
- Parents' levels of satisfaction with school staff were highest with classroom assistants (61%) and special educational needs co-ordinators (56%).

When we asked about people's views on education and social care provision for children, 44% of respondents said that services and support had got worse in the last five years. Only seven per cent said they'd improved.

What matters to you:

“ My granddaughter has no extra help at school. The staff are very understanding and make allowances for her, but she needs one-to-one help with her schoolwork and there isn't any available therefore she is falling behind academically. She is eight years old and had to sit a mandatory test the other week, she couldn't do it and had a meltdown and her mother had to collect her from school as she was so distressed. This is demoralising for her. ”

“ Pre-school system worked very well, quick diagnosis and good support but this all fell apart when our child got older. The difference was dramatic, and provision all too often poor. ”

An Autism Act for Wales

We propose that an Autism Act could include:

- ensuring local areas have a better understanding of the numbers of autistic children in their area to plan effectively for their needs
- ensuring that there is a clear framework for training for teachers.

A strategy and guidelines alone have been insufficient to make this happen. Legislation would make sure that autistic children and young people receive an education that sets them up for life, within a system that works for them and with their families. Teachers would be better equipped to teach autistic children and young people.

¹ School Action, School Action Plus and Statement are the terms used to describe the different levels of support provided in schools for children with special education needs



Autism is a lifelong condition and therefore autistic children grow up to be autistic adults.

Many people on the autism spectrum do not receive a diagnosis until adulthood. Because autism is a developmental condition, and not a learning difficulty or mental health issue, autistic people can often fall through the gaps when it comes to receiving the support they need. Access to services should be based on need and not a person's IQ.

With the right support at the right time, autistic adults can live fulfilling lives. However, almost half (49%) said that they didn't have enough support to meet their needs.

The survey shows that:

- Around half (48%) of adults who responded² said there was a lack of understanding of autism among professionals.
- Employment (55%), education (52%) and counselling (48%) were the main areas where autistic people would like more support.
- Only one in ten were in full-time paid employment.
- With more support:
 - 68% said they'd be able to express their needs and wants
 - 60% said their mental health would improve
 - 52% said they could live more independently.

When we asked about people's views on services and support for adults, more than a

third (35%) said that services and support had got worse in the last five years. Only 10% said they'd improved. However, several voluntary organisations, parent groups and charities across Wales were mentioned as providing invaluable support on a local level.

What matters to you:

“ There is a lot of talk about helping autistic people but little on-the-ground action in helping us better manage our differences and achieve our potential. ”

“ The lack of services in the adult sector is a huge concern – the difference once my son left school was marked. I worry a lot about the future. ”

“ Statutory services are a minefield and frightening – often individuals do not seek support until they are in crisis situations. To be made to jump through hoops to get even baseline support adds anxiety and stresses to an already difficult situation – people are simply lost in systems! ”

An Autism Act for Wales

We propose that an Autism Act could include:

- collecting data on the number of autistic people to ensure that local authorities and health boards can plan their support and services effectively
- ensuring local plans developed for services and support are based on need
- ensuring that access to health and social care services for adults are based on need and not IQ-related criteria.

A strategy and guidelines alone have been insufficient to make this happen. Legislation is needed to ensure that autistic adults aren't denied support because of their IQ and to empower individuals and parents to get the support they need.

² This includes parents or carers answering with or on behalf of their adult son or daughter



Most of the responses to our survey came from parents and carers of autistic people and they painted a very clear picture of the difficulties they face in getting support for themselves and the frustrations in dealing with the health and social care systems.

The survey shows that:

- Fewer than one in every five respondents (18%) had received a carer's assessment.
- Of those who had, just over half (54%) said they got any support as a result.
- Three quarters disagree that there is enough support for carers.
- Some 85% identified that a single point of contact is the most needed extra support they'd like to have.
- Seven out of ten carers said that they feel isolated.
- A fifth of those who responded said that they had to give up work.

When we asked about people's views on services and support for families and carers, 41% said that services and support had got worse in the last five years. Only six per cent said they'd improved.

What matters to you:

“ I sometimes feel overwhelmed. ”

“ I'm on a local carers' forum which is helping me get a Carer's Assessment as we have two diagnosed as having autism and one awaiting a [diagnosis] but no help, and no family in Wales to help. We realised recently that in a decade of living in this house we haven't (husband and I) had a single night out in this town. ”

“ It is constant and isolating. ”

“ I have lost my sense of self and my confidence... There is no time to think about life outside of the immediate stresses and ongoing assessments. ”

“ As parental carers we have been left at every stage to fight to get things in place. ”

An Autism Act for Wales

We propose that the Act could include:

- ensuring that specific support and interventions are provided for carers of autistic people, by making sure that a better understanding of need is built into local plans.

A strategy and guidelines alone have been insufficient to make this happen. Legislation would make sure that the specific needs of carers and parents of autistic people are met and they know what support they can expect at a local level.

The compelling need for change demonstrated by the experiences autistic people and their families shared with us for this report tells us that politicians need to Act Now for Autism and introduce an Autism Act for Wales in the next Assembly.

This is important for reaching our ambition to ensure that society accepts and understands autism and provides real opportunities for autistic people and their families to reach their full potential.

It is also important for Welsh Government to be showing leadership on this issue and save money while doing so. While there is always some cost involved in introducing new legislation, what we propose would not result in significant new burdens on local authorities and local health boards. In fact, we believe that by making duties much clearer money will actually be saved in the long run.

Local authorities already have to provide care and support services, including preventative services, for people under the *Social Services and Well-being Act 2014*. Failure to adequately provide these services can have costly consequences for individuals, as well as the state, through people falling into crisis situations and needing expensive services or residential care.

A report by the National Audit Office (NAO) stated that: “Beside the negative impact of such crises on a person’s life, acute services are also expensive, with inpatient mental health care costing between £200 and £300 per day.”³

As a result, the NAO report found that if local services identified and supported just four per cent of autistic adults, the outlay would become cost neutral over time. If they did the same for just eight per cent it could save £67 million each year.⁴

The responses to our survey, and the comments we received, clearly demonstrate the need for action and leadership on autism in Wales, to alleviate the frustration felt by autistic people, their families and carers. It’s time for an Autism Act for Wales.

“

If local services identified and supported just four per cent of autistic adults, the outlay would become cost neutral over time. If they did the same for just eight per cent it could save £67 million each year.

National Audit Office (NAO) report

”

³ National Audit Office. (2009). *Supporting people with autism into adulthood*. London: The Stationary Office

⁴ Ibid

ABOUT AUTISM



Autism is a serious developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a lifelong condition and children on the autism spectrum grow up to become adults on the autism spectrum.

More than 1 in 100 people in Wales has autism. It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways.

Some people on the autism spectrum are able to live relatively independent lives, but others may need a lifetime of specialist support. People on the autism spectrum may also experience over- or under-sensitivity to sounds, touch, tastes, smells, lights or colours.

About NAS Cymru

NAS Cymru is the leading charity for people on the autism spectrum and their families. With the help of our members, supporters and volunteers, we provide information, advice and support services, and campaign for a better world for autistic people.

Some 34,000 people in Wales have autism. Together with their families and carers, they make up the 136,000 people whose lives are touched by autism every single day.

NAS Cymru works across Wales for people affected by autism. We have 14 volunteer-led branches, as well as members across the country. They are at the heart of what we do. We provide advice and information, and campaign for lasting positive change for people affected by autism, and empower people to influence decision makers locally.

We also provide support and specialist services for adults across north and south Wales in a number of settings ranging from residential care, supported living, community-based resource centres, at university, and in people's own homes.

The National Autistic
Society Cymru

6-7 Village Way
Greenmeadow Springs
Business Park
Tongwynlais
Cardiff
CF15 7NE

Tel: 029 2062 9312

Autism Helpline: 0808 800 4104

Minicom: 0845 070 4003

Email: wales@nas.org.uk

Web: www.autism.org.uk/wales

JOIN US at [facebook.com/NASCymru](https://www.facebook.com/NASCymru) • FOLLOW US @NASCymru #ActNow