

think
differently
about
autism

I Exist

The message from adults with autism in Northern Ireland



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The National
Autistic Society
Northern Ireland

Your autism charity

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Contents

Executive summary	1
What is autism?	3
Introduction	4
Chapter one: <i>Think differently</i>	6
Chapter two: <i>Understand my needs</i>	10
Chapter three: <i>Act positively</i>	16
Chapter four: <i>Transform lives</i>	22
Conclusion	28
Appendix one: Methodology	30
Appendix two: Glossary of terms	31



Executive summary

For too long, adults with autism have found themselves isolated and ignored. They struggle to access support and are often dependent on their families. This report considers the experiences of adults with autism and their families in Northern Ireland and examines the changes that are needed to transform their lives.

Think differently

The research underpinning this report reveals that 90% of people in Northern Ireland do not know how common autism is – 24% believe it affects 1 in 10,000 people; 38% believe it affects 1 in 1,000 people. In fact, autism affects 1 person in every 100.

Our research also reveals a widespread misconception about the age range of people affected by autism, and whether the condition can be cured. 55% of those who have heard of autism believe that it mostly affects children. In reality, autism is a lifelong condition. Children with autism grow into adults with autism.

Act positively

These long-held misconceptions continue to have a profound impact on the lives of adults with autism in Northern Ireland. They lead to a lack of appropriate service provision and result in near total social exclusion for the adults affected. 96% of the adults who took part in our survey feel that with more support they would be less isolated. As a direct result of this lack of support, 34% of adults in our survey have experienced severe mental health difficulties and 57% have suffered from depression.

We urge the Northern Ireland Assembly to take action to provide the support that adults with autism so desperately need.

Transform lives

The Northern Ireland Assembly should ensure that its ASD¹ Strategic Action Plan² meets the needs of adults with autism. The plan should be fit for purpose to ensure that:

- > local Health and Social Care Trusts record the number of adults with autism in their area
- > there is a named professional responsible for diagnosing adults with autism in each Trust area
- > Health and Social Care Trusts establish a clear route to enable adults with Asperger syndrome or high-functioning autism to access assessment and support
- > health professionals who are in regular contact with adults with autism are properly trained
- > adults with autism and their families and carers are involved in the development of services
- > new autism-specific services are developed for adults, families and carers.

The Northern Ireland Assembly should also ensure that there are clear accountability mechanisms in place to monitor the implementation of the ASD Strategic Action Plan.

The plan should:

- > have clear targets that are time-specific and meet the needs of adults with autism
- > have adequate ring-fenced funding to ensure its delivery
- > be subject to an annual review by the Health, Social Services and Public Safety Committee to ensure that targets are met and consistent progress is made across all Trusts.

¹ Autism spectrum disorder

² On 17th September 2008, Health Minister Michael McGimpsey launched a consultation on an action plan to improve autism services for individuals of all ages affected by autism, their families and carers. This was a response to the recommendations of the Independent Review of Autism Services, chaired by Lord Maginnis (see page 4).

I Exist is the message from adults with autism.

Most are isolated and ignored. Think. Act. Transform lives.

What is autism?

Imagine waking up in another country where nobody speaks your language, and people live by a set of rules that are completely unfamiliar to you.

How would you cope if you didn't understand the rules?

To varying degrees this is how people with autism experience their surroundings every day.

Autism is a 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 serious, lifelong and disabling condition. Without the right support, it can have a profound – sometimes devastating – effect on individuals and families.

Autism is a spectrum condition, frequently referred to as Autism spectrum disorder (ASD), which means that, while all people with autism share three main areas of difficulty, their condition will affect them in different ways. The three main areas of difficulty are:

- **social interaction:** it can be harder for people with autism to recognise and understand other people's feelings and express their own, making it difficult for them to 'fit in' socially. Many adults with autism say that they are socially isolated and that their family is their only form of social contact.
- **social communication:** people with autism can find it difficult to use and understand language (both verbal and non-verbal) to different degrees. When talking to professionals, adults with autism will benefit from meetings which are set up to take account of their preferred style of communicating. They may like to have an advocate present

who can help them express their needs and aspirations

- **social imagination:** people with autism can find it hard to imagine situations outside of their own routine, and therefore to plan for the future, cope with change or manage in new and unfamiliar settings. They may also find it hard to understand and predict other people's intentions and behaviour.

People with autism may also experience sensory sensitivity – being over- or under-sensitive to sound, touch or light, or certain tastes, smells or colours.

Some people with autism also have an accompanying learning disability.

Research has shown that 1 in 100 children has autism. Very little is known about how many adults have autism, but by applying the 1 in 100 figure to the general population, we can estimate that there are more than 17,000³ people with autism in Northern Ireland, the majority of whom are adults.

In this report we use the term autism to describe all diagnoses on the autism spectrum, including Kanner autism, Asperger syndrome and high-functioning autism.^{4,5}

³ The limitations of this prevalence figure are explored in chapter three.

⁴ While high-functioning autism is not officially recognised clinically as a diagnostic term, some people have this as their diagnosis or identify with this term, and for this reason we use it in this report.

⁵ Other terms, such as autism spectrum disorder (ASD), are used in the report only when they are direct quotes from people or publications.

Introduction

"I spent last Monday sitting still, holding my head and worrying – alone."

Adult with autism

"The simple reality is that he needs 24-hour supervision. He's not safe to go out on the road by himself so even when getting him in and out of the car we are always careful to make sure he doesn't go off in the wrong direction... his self-help is very, very limited."

Parent

"Who will look after my daughter if I am ill or pass away? No one has the answers."

Parent

I Exist is a new campaign by The National Autistic Society Northern Ireland. Through it we want to share the experiences of the many adults with autism in Northern Ireland who struggle to get the understanding and support that they need.

I Exist is based on a survey of adults with autism and their families in Northern Ireland and a set of in-depth interviews with adults who have complex needs. The results provide a snapshot of the daily lives of people living with autism. The campaign is also informed by a survey of public attitudes towards autism and interviews with the five Health and Social Care Trusts in Northern Ireland.

Our campaign follows Minister Michael McGimpsey's welcome announcement of an Independent Review into Autism Services in Northern Ireland. The Review, chaired by Lord Maginnis, delivered its report in June 2008.⁶ The report outlines a series of important recommendations, and states that resources are urgently needed to improve service provision in Northern Ireland for people with autism and their families.

⁶ The independent Review of Autism Services, chaired by Lord Maginnis of Drumglass, can be found on the Department of Health, Social Services and Public Safety website at http://www.dhsspsni.gov.uk/independent_review_of_autism_services_final_report.pdf

"While there has been some 'baseline' progress over recent years towards the development of ASD-specific diagnostic services in Northern Ireland for children, the same cannot be said for older adolescents and, in particular, those presenting for the first time in adulthood. The review has identified a significant gap in terms of services for adults, not only within the HSC⁷ sector, but across a range of statutory service providers. It is recommended that this unsatisfactory situation should be changed as soon as possible."

*Independent Review of Autism Services*⁸

Adults with autism in Northern Ireland have been ignored for too long and appropriate services have not developed at a pace to meet their needs. Our research demonstrates the desperate need for the Independent Review recommendations to be fully implemented through the ASD Strategic Action Plan, and for words to be transformed into action.

⁷ Health and Social Care

⁸ Department of Health, Social Services and Public Safety. (2008). *Independent Review of Autism Services*, page 16. Belfast: DHSSPS

Gary



Gary is 24 and has autism and a learning disability. He is non-verbal.

"He was a wild child and really hard to manage while going through his childhood - but as he grew into an adult he calmed down to the point where he became almost too calm... He had to be stimulated to do almost anything at all."

Gary lives with his parents and attends a day centre four days a week. He goes to a sheltered workplace once a week. He is highly dependent on his parents for support.

Gary's parents feel that appropriate respite care is not available in their local area. Although there is a respite service that they can use once or twice a year, the service providers are not specialists in autism. Gary is in a very loving home and his parents meet all his needs, 24-hours a day - but they too require support in their role as carers and deserve the chance to live their own lives as fully as possible.

"Our needs and Gary's needs are not the same. From our perspective I guess we would like a little more freedom. The provision that we have tends to be quite rigid and structured so we don't have the flexibility to do something just because we would like to do it. From Gary's point of view we have always said we would like quality provision rather than a lot of provision. *We will look after Gary and for as long as we are able.* We don't want to be unhappy if we go away for a weekend, knowing that he is stressed because he is in an inappropriate environment."

Chapter one: Think differently

"I don't think there is a lot of understanding of autism... it's so different from any other disability... People would have felt sorry for you if they saw a child in a wheelchair, whereas my son would have been up to all kinds of 'devilment' so in their eyes he was just a spoiled child."

Parent

"People don't understand what autism is. I worry that [my son] won't cope in society after I am gone."

Parent

Every day, The National Autistic Society Northern Ireland hears from people affected by autism who are suffering due to a lack of awareness and understanding of the condition among professionals and the public. We hear about intolerance, discrimination and isolation; we hear about problems at work, at school, at home; we hear about assumptions and misconceptions amongst the general public and within statutory agencies.

For people affected by autism, this lack of understanding leads to a lifetime of exclusion - exclusion from life in the community, exclusion from employment, exclusion from education - and prevents them from getting the help they need to live fulfilling lives.



Public attitudes to autism

In August 2008 we commissioned a leading market research company, GfK NOP, to survey a sample of the Northern Ireland population on their awareness and understanding of autism. A representative sample of five hundred people aged 16 and over was surveyed across six counties in Northern Ireland. As a result, we have been able to compare the everyday experiences of adults with autism with public perceptions of the disability.

We found that:

- > the public do not realise how common autism is
- > awareness of autism is high but awareness that Asperger syndrome is a form of autism is low
- > there is a misconception that people with autism have special abilities
- > there is a mistaken belief that autism mostly affects children.

Key survey findings

i) *Autism is much more common than people realise*

We asked our respondents what proportion of the population they thought were affected by autism. The vast majority – 90% – didn't know how common autism was. 24% thought autism affected 1 in 10,000 and 38% thought it affected one in 1,000.

In fact, there are an estimated 17,000 people in Northern Ireland with autism – that's one in 100. If you include their families, autism touches the lives of over 68,000 people in Northern Ireland every day.⁹

⁹ The limitations of this prevalence figure are explored in chapter three.

¹⁰ Hermelin B. (2001). *Bright Splinters of the Mind*. London: Jessica Kingsley

Awareness of autism amongst the general public in Northern Ireland is high, but awareness that Asperger syndrome is a form of autism is low. Our survey reveals that 87% of the population have heard of autism but far fewer people – only 48% – have heard of Asperger syndrome.

ii) *There is a lack of awareness and understanding of autism*

There was considerable confusion in our survey about the nature of autism. We asked the public to identify the key characteristics of autism from a list of typical behaviours and perceptions, some of which were unrelated to the condition.

Encouragingly, many people correctly identified some of the key characteristics of autism: 90% of those who had heard of autism were aware that people with autism had difficulty communicating with others; 91% were aware of resistance to change in routine; 84% were aware that people with autism had difficulty in making sense of the world; 79% were aware that they have difficulty making friends and 84% were aware of obsessive behaviours.

However, a significant proportion of respondents (48%) believed incorrectly that people with autism swear inappropriately, while 24% thought people with autism were intentionally rude and 11% thought they were unable to walk.

The proportion of respondents who believe that people with autism have special abilities in, for example, maths or art, is 62%.

In fact it is estimated that only 1 in 200 people with autism have 'savant' special abilities.¹⁰

Widespread misconceptions such as these make it all the more difficult for people with autism to get the right kind of support or, in many cases, to get any support at all. An apparent ability in a certain area may lead people to underestimate the challenges an

individual faces in other parts of their life; a person with autism may have a degree but still be unable to live independently without the right support.

iii) *A majority of people don't know who is affected by autism*

Our survey revealed a widespread misconception about the age range of people affected by autism, and whether it can be cured. 55% of those who have heard of autism believe that it mostly affects children.

In reality, autism is a lifelong condition. Children with autism grow into adults with autism.

This combination of myth and misconception has a direct impact on the way the public reacts to and behaves towards adults with autism. This in turn impacts on the experiences of those people living with the disability day in, day out.

On a positive note, 83% of respondents to our survey indicated that they would be comfortable working with a person with autism. This suggests that there is scope for the greater inclusion of people with autism in the workplace. Inevitably, however, there is often a gap between people's good intentions

and the reality of working life. Appropriate training and support for employers and employees is necessary to ensure that people with autism are welcomed into the workplace and supported on a day-to-day basis.

Think differently about autism

Our public attitudes survey highlights some of the major gaps in the public's perception and understanding of autism. Increased awareness is vital to ensure that adults with autism and their families are able to participate in society and get the support and services they need.

This lack of awareness does not only occur among the general public. Adults with autism report that many key professionals, such as GPs and social workers, do not have an adequate knowledge of their condition either.

We all need to improve our understanding of what it is really like to live with this lifelong condition. We all need to *think differently about autism* so that people who have the condition are able to enjoy the life opportunities that other people take for granted.

Stepping Stones

Stepping Stones is a community business based in Lisburn¹¹ that provides vocational training for people with learning difficulties through its coffee shop, craft shop and picture-framing business.

At Stepping Stones, a number of young people, some of whom have autism, have been helped to learn new skills and develop independence, leading them into supported employment. Adults with learning disabilities can access accredited training in areas such as Catering and Retail, Basic Food Hygiene, Health and Safety and Customer Service, while the STEP programme assists people with disabilities in finding and keeping a paid job with ongoing support.

Stephen Gillespie, a young man with autism, completed the STEP programme and is now a paid employee of Knox and Clayton Architects. He says: "Paid employment has done wonders for me, and will continue to do so for many years to come."

¹¹ For more information about this project, visit www.stepping-stones.org.uk

Graham



Graham is an adult with Asperger syndrome. He is a graduate of Cambridge University and is in full-time employment.

"I got the diagnosis of Asperger syndrome largely because I have two boys who were diagnosed with Asperger syndrome... a lot of the things that [I did] I thought were normal... and therefore when it was happening to my children I just thought that was the way people were... It became obvious from my reading that was not the way people were."

Graham had been having problems at work prior to his diagnosis; this resulted in depression and a great deal of stress. One of the ways he tried to combat his difficulties was through 'Talk Therapy'.

"If you go along to Talk Therapy... and you are talking in Aspergers and they are talking in normal speak, it is a recipe for disaster. If someone gives me psychological advice which they intend to be taken with a pinch of salt, I will take it literally... to be honest this made things disastrously worse."

Graham experiences some sensory issues. He has an over-sensitivity to noise, so bells and loud music can be painful. So far, none of the services that Graham has encountered have been particularly helpful.

"I perhaps got very badly burnt by the process of counselling and I am very reluctant to go back to that sort of health professional service. When I have seen some of the services locally that people were trying to give to people with autism, to the boys, I found it very depressing... their model for dealing with people with autism was to try to deliver the needs in a way that they would deliver to someone without autism."

Chapter two: Understand my needs

"I do very little with my days. I am suffering terrible depression."

Adult with autism

"I took the dog for a walk, stayed in the house for the rest of the time."

Adult with autism

"I got up at 9.30. Washed, shaved. Went to town with father to do some messages. Came home. Made lunch. Rested on bed for 2 1/2 hours, came down, made tea, went to bed at 10.30."

Adult with autism

We have seen how public perceptions of autism are all too often based on myth and misunderstanding. In reality, autism affects no two people in the same way – it is a complex disability and the individual experiences of people with autism are equally complex. Yet what unites them is the ongoing struggle to get the support they need.

To understand the difficulties that adults with autism in Northern Ireland face, we must first listen to their experiences, and those of their parents and carers.

We're isolated

Adults with autism frequently struggle when communicating with other people. This can make any kind of social situation extremely difficult. The social and communication difficulties faced by adults with autism can mean they often find themselves isolated, with no meaningful companionship and few activities to fill their day.

35% of the adults with autism in Northern Ireland who responded to our survey find it hard or very hard to make friends, and 28% say that they have no friends at all. Without appropriate help, many face complete social exclusion.

This lack of companionship and meaningful activity is also a source of concern for parents of adults with autism.

"He has to be motivated to get up, usually not until the afternoon; he does not prepare or eat any meals until I return from work at 5pm. He spends all his time in front of the TV and retires to bed in the early hours."

Parent

"I worry about isolation, depression and [my son] being exploited."

Parent



We want to be included

It would be wrong to assume that adults with autism do not want to interact socially with other people – 79% of adults in our survey would like to spend more time in the company of others. Adults with autism desperately want to overcome the barriers they face and they can do so if they receive the right support to meet their individual needs.

70% of the adults with autism in Northern Ireland who took part in our survey do not have enough support to meet their needs, and 96% of those feel that with more support they would be less isolated. This lack of support can have a profound impact not just on adults with autism but also their families.

"No one helped after diagnosis – I was left totally alone to deal with my diagnosis and there was no further input from professionals."

Adult with autism

"My son is socially and economically isolated – he gets no support from his local health service whatsoever. I am his principal carer and I get no support either. I care for him (along with my wife) as best I can. I am almost 59 and I still need a life of my own. We have three other children who need to be cared for and supported."

Parent

"There were never any interventions in over 30 years, despite clear behavioural and social problems at school."

Parent

The impact of a lack of support

Without appropriate support, adults with autism experience profound social exclusion and isolation and are often left to struggle through life.

As a direct result of this lack of support:

- > 34% of adults with autism in our survey have experienced severe mental health difficulties
- > 65% of adults with autism in our survey have experienced anxiety
- > 57% of adults with autism in our survey have experienced depression.

"The slightest change in arrangements upsets him. It panics him – he suffers from eczema and this causes him to scratch his face. He has no confidence in anything that he does – he has to check and recheck. He does not trust doctors or nurses."

Parent

Adults with autism can find themselves in a highly vulnerable position as they try to get through each day without support. 50% of adults with autism in Northern Ireland who responded to our survey have experienced bullying or harassment since turning 18.

"I work in an environment where I am not understood and I am bullied by those who do not understand."

Adult with autism

"As I have been accused of bullying the people who have bullied me, I am currently suspended from work pending an investigation. I spent last Monday sitting still, holding my head and worrying – alone."

Adult with autism

"He doesn't speak, doesn't do anything on his own initiative and so needs continuous support."

Parent



Social groups

The National Autistic Society has established a UK-wide network of social groups for people with Asperger syndrome and high-functioning autism. The aim of these social groups is to help adults develop their social and communication skills and overcome their social isolation.¹²

Our social groups are aimed at people over the age of 16 who want to socialise and meet with other people who have Asperger syndrome and high-functioning autism. The groups meet once a month and are organised and arranged around the interests of their members. As a group, the members decide for themselves what they would like to do. Some choose to take outings to pubs and restaurants, others have gone kayaking, visited the cinema, played golf or sometimes just met for a chat. We already run five such social groups in Northern Ireland and our aim is to double this number in the near future.

¹² Further information about NAS social groups can be found at www.autism.org.uk/socialgroups

The impact on families

The reality for most adults with autism is that they depend solely on their families for support. 64% of adults with autism in our survey live at home with their parents. Only 13% live on their own. Most need some form of financial support; only a quarter are financially independent.

"For five years I have supported him, but financially I can't continue - particularly in relation to accommodation."

Parent

If the current failure to meet the needs of adults with autism is not addressed, an inevitable crisis situation will develop, not just for the adults themselves but also for health and social services. Adults with autism who rely solely on their parents for support must eventually face a time when their parents are no longer there for them. If they have not already received support to enable them to lead a more independent life, it is likely that very complex needs will arise that will require high levels of assistance.

According to our survey, 83% of parent and carers in Northern Ireland are worried about their son or daughter's future when they are no longer able to support them.

"I am my son's only parent and I fear for the future when I am not here."

Parent

"The future is always a worry, unresolved as it is."

Parent

Our survey reveals that parents and carers of adults with autism who live at home are rarely given the support they need in their role as carers. 55% have not received a carer's assessment and 52% receive no support at all from social services. When asked what they felt were the barriers to the person they cared for receiving support, 40% highlighted inadequate funding, 24% a lack of understanding of autism and 36% a lack of understanding of the needs of people with autism.

Improving the lives of adults with autism

If adults with autism receive the support they need at the right time they can lead more independent, productive and fulfilling lives.

"[My psychologist] was essential in many ways to the support I got... Her support helps me to keep my feet on the ground. It helps me to keep a certain amount of control, just to make sure that I don't lose touch with the world that I'm in."

Adult with autism

Regrettably, not all adults with autism benefit from this level of help. For the majority, life will only improve once they and their families receive timely, appropriate services that meet individual needs and circumstances.



Artwork by Mike, a man with autism. Mike is non-verbal and his drawings record the things he has seen or done during the day.



Robert



Robert is 29 and lives at home with his mother. He received a diagnosis of Asperger syndrome when he was 14. Robert is an intelligent young man and has benefited from the support of his family and his psychologist, whom he says "keeps him grounded".

Robert is extremely interested in video gaming and spends a lot of time on his computer. He has a fantastic talent for voiceovers and has set up his own website with the help of his brother in order to further this interest. Intellectually, Robert is very capable, but he can only manage everyday activities with support from his mother.

"With me it's still a work in progress. It has been slow trying to accept the responsibilities of the full daily grind. To a degree I am still working on self-help... My mum still has concerns... time is pressing on for her because she is in her mid-sixties now."

Robert says he would find life very difficult without the support of his family.

"If I were by myself, I know that I would in many ways lose perspective."

Chapter three: Act positively

"The big paucity of services is for adults with high-functioning autism and the other big issue is that there is a lack of respite services. There is a lack of specific services which are tailor-made for people with autism."

Health and Social Care Trust

"There is very little available for adults with an ASD who present as able but require occasional fall-back support if and when they become overwhelmed."

Parent

There are a number of specific barriers that prevent adults with autism in Northern Ireland from accessing the services and support they need. Many of these stem from a lack of understanding of autism, and from inadequate service provision and information systems within local Health and Social Care Trusts.

Health and Social Care Trusts are very candid about the lack of services for adults with autism in Northern

Ireland. As a general pattern, resources have been concentrated on the provision of services for children.

"The focus seems to have been on children. All the resources seem to have focused on children and the adult population have basically been invisible - nobody's thought of them at all."

Health and Social Care Trust



More information would lead to better services

A major barrier to providing effective services and support to adults with autism is that local Health and Social Care Trusts in Northern Ireland do not know how many adults with autism live in their area. As a result, these adults are 'invisible' to local services and the wider community.

The collecting and sharing of information about adults with autism would ensure that the individuals who require support are identified and the local Health and Social Care Trusts can plan and develop services to meet their needs.

Current systems for recording the number of children and adults with autism in Northern Ireland are inadequate. It is estimated that there are 17,000 people in Northern Ireland with autism, yet very little is known about the true number of adults with the condition in this country. In our interviews with the five local Health and Social Care Trusts, we found that there were no accurate records of the number of adults in any Trust area. In fact, only a limited amount of local data is collected, despite there being widespread recognition of the problem.

"To be honest we have to recognise that, certainly in this directorate, we haven't any means to collect that data or indeed record it, because all of our records are manually held. We have no information systems that allow us to collect data about diagnosis or need, so outside of people who have autism and learning difficulties or autism and mental health problems, we have no records."

Health and Social Care Trust

This situation is further exacerbated by the considerable backlog of people waiting to receive a diagnosis in certain parts of Northern Ireland. This backlog means that Health and Social Care Trusts would struggle to identify the true number of people with autism in their local Trust areas, even if they had an adequate system in place to record them.

A lack of accurate data on the number of adults and children with autism has been highlighted by the Independent Review into Autism Services in Northern Ireland:

"The Review notes that, for a variety of reasons, existing information systems within Trusts do not provide an accurate picture of the true number of ASD cases within the general population. In addition, given the limited level of ASD services, the number of cases diagnosed at present may not reflect the true number of cases."

"Accurate up-to-date information is needed to inform a plan for an appropriate assessment process. The review therefore notes the need to establish effective, robust information systems capable of providing up-to-date information on the numbers of people affected by ASD in Northern Ireland."¹³

It is essential that this information is collected in order to develop appropriate services for all people with autism. Without it, local Health and Social Care Trusts have no way of calculating how many adults require support either now or in the future, or what demands will be placed on the services they provide. The specific needs of a significant and vulnerable section of the population in Northern Ireland will continue to be overlooked when planning and providing services.

Systems need to be in place to record both children and adults with autism. Periods of transition can be very challenging for people with autism, who often depend on routine and structure to help them

make sense of their environment. The stress caused by change is made worse when young people who had previously been receiving services have that support taken away because of a failure in communication and a lack of planning between services. It is therefore vital that information about children with autism who have been identified at a young age and are receiving health or social services is passed on to adult services in preparation for their transition to adulthood.

Access to diagnosis is extremely limited

Getting a diagnosis can sometimes make it easier for adults with autism to access services, even though support should be based on need and not diagnosis. Many adults grew up in a time when there was even less awareness and understanding of autism than there is now. The needs of these adults were not recognised in childhood and they are only now being understood.

Nevertheless, 60% of adults in our survey have found it hard to get a diagnosis. This is not surprising given that there is no one employed in any of the five local Health and Social Care Trust areas to specifically diagnose adults with autism.

The arrangements for diagnosis vary across Trusts. In one Trust area, a small number of psychologists will diagnose as a minor part of their clinical work. In other areas there appears to be an informal arrangement where psychologists working with children will, on occasion, diagnose adults.

The process of seeking a diagnosis can be a long and difficult one and, without a diagnosis, many adults with autism remain invisible to local services and their needs remain unmet.

"Undiagnosed ASD hindered his schooling. He has difficulty with arithmetic, reading and can't mix with people. He can't use public transport."

Parent

"I had to pay for and ask for a diagnosis. The psychiatrist missed it so I went private."

Adult with autism

"Diagnosis was the most anxious period of my life."

Adult with autism

It is important that all adults are able to access a timely diagnosis in their local area and that it is carried out by appropriately trained professionals. It is also extremely important that individuals with autism are supported during and after the diagnosis process.

"It took five years to get a diagnosis and there is no further help available."

Adult with autism

"I did not know how to ask for support or where to go to ask for it."

Adult with autism

Difficulties accessing a Community Care Needs Assessment

Community Care is the name given to the services provided to help vulnerable members of society to live as independently as possible. These people include those with disabilities such as autism, older people and people with mental health difficulties. Health and Social Care Trusts have a duty to carry out an assessment of any person in their area who may be in need of Community Care services. Yet despite this duty, only 27% of the adults with autism who responded to our survey have had an assessment of their needs undertaken by their local Trust.

It is essential that any professional who carries out a Community Care assessment of an adult with autism understands the nature of the disability. It is also vital that they know how to communicate with a person with autism in order to assess their needs accurately. To

¹³ Department of Health, Social Services and Public Safety. (2008). *Independent Review of Autism Services*, page 44. Belfast: DHSSPS

communicate effectively, they will, for example, need to give consideration to the person's preferred method of communication, set up meetings at times that suit the person, provide access to an advocate and involve people who know the person with autism well. It is important to understand the difficulty some people with autism have in defining what their needs and aspirations are – some people with autism might say what they think the assessor wants to hear, in an attempt to please them, rather than provide an accurate answer.

Following a Community Care assessment, the Trust will decide whether the needs of the person in question fall into the category of critical, substantial, moderate or low, and should then direct that person to the appropriate services. But even if the Trust recognises that an adult with autism has unmet needs, this does not necessarily mean that they will receive support to meet those needs. It is up to each Trust to decide at what level it will provide support. So, for example, one Trust may fund services for all those with critical and substantial needs, while another Trust may only fund services for those it considers to have needs at the critical level.

47% of adults in our survey had problems receiving support from Health and Social Care Trusts. Given that it is so difficult to obtain services from local Health and Social Care Trusts, it is essential that adults with autism are given an assessment by someone who at least understands their condition.

Bridging the gap between mental health and learning disability services

Many adults with autism find that they are unable to access an assessment because the structure and organisation of local services discriminates against them. Many find themselves excluded from any type of service, particularly if they have Asperger syndrome or high-functioning autism.

Autism is neither a learning disability nor a mental health problem; it is a developmental disorder. But people with autism who come into contact with their local Health and Social Care Trust tend to be directed toward either the learning disability or the mental health teams. Those adults who have no accompanying learning disability or mental health problem do not fall into either service category. The learning disability team therefore often refuses to get involved in their case, because they do not meet the correct criteria, while the mental health team often turns the person away as they do not have a mental health difficulty. This means that many people fall through the gap between mental health and learning disability services and end up receiving nothing. This is a significant failing in service provision and has serious consequences for many adults with autism.

This unsatisfactory situation has been recognised by local Health and Social Care Trusts:

"At the moment anyone who is currently sitting in learning disability services would also have a clear diagnosis of learning disability. They wouldn't be sitting there only with an autism diagnosis, and that's the problem. Both services don't want to see anyone unless they have an active mental illness or a determined learning disability, so the people outside of that tend to get nothing at the moment."

Health and Social Care Trust

"Adults with autism who don't have a learning disability or mental health problem, there's no defined place for them... the way we have developed our programmes of care makes it difficult to see where adults with autism sit and who should be taking the lead responsibility for developing those services."

Health and Social Care Trust

The Independent Review into Autism Services in Northern Ireland indicates that existing criteria should not be applied when assessing adults with autism, instead highlighting the importance of individual need:

*"The Review team recommends that access to services should be determined by the individual needs of the child or adult, and the family. This would also be in line with policy and practice recommended by the Department of Health in England."*¹⁴

The structural disadvantage faced by adults with autism is exacerbated by the lack of a clear line of responsibility for ensuring that their needs are met. Leadership at a local level is needed in order for this to change. The Independent Review into Autism Services proposes that an ASD-specific team should be established in each Trust area to work with older adolescents and adults with an ASD.¹⁵



Befriending schemes

Befrienders are volunteers for The National Autistic Society Northern Ireland who spend a few hours each week with an adult or a child on the autism spectrum, or their family. The scheme is designed to create opportunities for social inclusion for the person with autism and provide additional support for their parents or carers.¹⁶

Befrienders and befriendeds are matched as closely as possible through shared interests and enthusiasms, as well as their other commitments and geographical location. Some befrienders may spend time in the family home whilst others may go out and about with their befriendeds on trips to the cinema, to restaurants, or to the park. Befrienders play a vital role in minimising the isolation of families and individuals who are affected by autism. The scheme currently operates in a number of locations around Northern Ireland and we are seeking to extend its reach so that as many adults with autism and their families as possible can benefit from it.

Photo collage above by Penelope Dunbar, a woman with Asperger syndrome. She describes that it "allowed me to gain insight into an important aspect of my disability which I struggle with on a daily basis".

¹⁴ Department of Health, Social Services and Public Safety. (2008). *Independent Review of Autism Services*, page 39. Belfast: DHSSPS

¹⁵ Department of Health, Social Services and Public Safety. (2008). *Independent Review of Autism Services*, page 52. Belfast: DHSSPS

¹⁶ Further information about the NAS befriending scheme can be found at www.autism.org.uk/befriending

Jason



Jason is nearly 19 years old and lives with his mother. He has autism, a learning disability, epilepsy and spina bifida. He is dependent on his mother for support.

"Days vary with Jason. One day he might just want to lie about all day in his room. I think what motivates him on a school day is the bus. He likes to be out in the car and on the bus."

Jason enjoys massage and reflexology because it is relaxing and helps to relieve his stress. Although he enjoys this activity, his mother says that sometimes he still refuses to enter the room "because something bothers him and he can't tell me. I had booked a session of reflexology for him and we drove off and when we got there he wouldn't get out of the car."

Jason has a keen sense of humour and he and his mother often "have a great laugh". Jason enjoys a lot of everyday activities and his mum says he likes to be kept occupied and this helps with his behaviour. His mum would like Jason to be able to attend more social activities.

"He has nothing. That's the one thing I would really like for him - one youth club or one night out of the house."

Jason is still in full-time education but will soon make the transition from education to adult services. This is causing concern for his mother as she feels "there are not many services available for people like Jason". She would like provision that not only contributes to Jason's quality of life but also boosts his self-esteem.

Jason's mother would like to see her local Health and Social Care Trust consult with parents and people with autism when developing services to ensure that adults with autism receive services that meet their needs.

Chapter four: Transform lives

"I always will need support because I am severely affected by Asperger syndrome... I can be very reclusive. I will never be fully independent."

Adult with autism

"He constantly needs reassurance in everything he does."

Parent

"He needs support getting up and going out to work... He can't really fend for himself in terms of feeding."

Parent

Adults with autism say they need a range of support, yet many receive little or no help. The Independent Review into Autism Services was very clear about what it sees as the "almost absent" level of services for adults with autism in Northern Ireland. The review calls for urgent action and the necessary resources to address this situation.

"To address the almost total absence of ASD-specific services for older adolescents and adults, the review team recommends an initial level of service investment to begin the process of service development - an investment of circa £1 million to provide an initial foundation level resource of 18.0 whole-time equivalent practitioners across the five trusts in Northern Ireland. This cannot represent the longer-term vision for services for older adolescents and adults and should be considered an 'initial' start-up resource. The review team therefore proposes that the impact of these resources should be reviewed after the proposed resource has been put in place. This would allow a longer-term plan for services for older adolescents and adults to be made - given the time needed for such services to be put into place, this could be undertaken by 2012/13. It is difficult at this time to establish the gap between existing (almost absent) and the 'ideal' level of service provision."

Independent Review of Autism Services¹⁷

Given that there is an almost complete absence of services for adults with autism in Northern Ireland, urgent action is needed to establish services that meet the individual needs of those adults. A person-centred approach is required and those providing the support should be trained in autism. Crucially, adults with autism and their parents and carers should be consulted at every stage of the development of these services.

¹⁷ Department of Health, Social Services and Public Safety. (2008). *Independent Review of Autism Services*, page 63. Belfast: DHSSPS



The importance of person-centred planning

Those adults with autism who do receive some level of support often find that it is not appropriate to their needs.

"What we see are the facilities for people with severe mental disabilities... where there's a high level of supervision and where the facilities are almost secure. At the other end of the scale there are facilities for people who are higher-functioning... where there is not a particularly high level of supervision; the doors are often not even locked. Neither of these is appropriate for [our son] because he isn't disturbed in the sense of making lots of noise or self-harming. On the other hand,

he doesn't have the mental capacity to function with a low level of supervision."

Parent

The diversity and individuality of autism means that no two people are affected in quite the same way. Therefore, services should be built around individual needs, rather than on the assumption that what suits one person will also suit another. A person-centred approach is required, which involves listening to the individual and making sure they are always at the centre of planning and delivering services. Unfortunately, there is still a long way to go before person-centred planning becomes a reality for adults with autism in Northern Ireland. Only 13% of adults with autism who responded to our survey currently have a person-centred plan.

Direct Payments

The Carers and Direct Payments (Northern Ireland) Act 2002 enables individuals who qualify for services from their local Health and Social Care Trust to opt to receive these in the form of a Direct Payment instead of services from the Trust. Where Direct Payments are available, they give people the financial resources to pay for their own services, rather than receiving them direct from their local Trust. They are then able to take control of the support they receive and choose services that meet their individual needs.

Social Care Trusts are committed to extending the scope of Direct Payments to those who are currently entitled. However, in Northern Ireland only 20% of respondents to our survey were in receipt of Direct Payments. This may be due to a lack of

knowledge about Direct Payments but could also be because of a lack of funding. The NAS has received reports of people qualifying for Direct Payments but subsequently being told that this would be classed as an unmet need because the funding was unavailable.

"It was a fight but thank goodness they have left me to my own devices. I highly recommend [Direct Payments]. It gives choice and control - very important."

Adult with autism

"I applied for Direct Payments but no funding was available."

Adult with autism

"We currently don't have anybody with autism who is accessing a Direct Payment."

Health and Social Care Trust

Asperger Syndrome and High-Functioning Autism Project in Down Lisburn

The Asperger Syndrome and High-Functioning Autism Project is based in the Down Lisburn area of the South Eastern Health and Social Care Trust. The project is informed by The National Autistic Society's Good Practice Guidelines.¹⁸ The project aims to identify the prevalence of people with autism in its area and develop a service based on their needs and those of their family, carers, partners or spouses. The project also involves delivering training in Asperger syndrome and high-functioning autism to co-workers in the Down Lisburn area.

The project is founded on a person-centred approach and provides the following supports:

- > an autism training programme for co-workers
- > employment opportunities and support
- > an advocacy service for clients and carers
- > more suitable service provision
- > therapeutic interventions to reduce social isolation
- > access to better social and academic support
- > therapeutic interventions to reduce mental health difficulties
- > interventions to develop independent living skills and relationships
- > therapeutic support for families
- > better post-diagnostic support
- > a focus on carers' needs
- > housing options.

An independent evaluation of the project was carried out by Queens University in which service users reported that it made an extremely positive impact on their life.¹⁹ Adults said that the project added to their quality of life through raised levels of happiness, increased self-confidence, enhanced self-sufficiency, improved communication skills, reduced social isolation and greater optimism about the future.

"This project... it's a lifeline. I couldn't go back to the way it was before. It's too awful even to think about going back to how it was."

Adult with autism

"It's brought out a young woman I didn't know was there but always hoped I would see."

Parent

The independent evaluation found that this project was delivering appropriate services to a group of people whose needs were not previously being met. They were either 'falling through the net' or were being placed inappropriately in mental health services, or even prison.

Funds for an additional project to service the Ards/Down area have now been made available by the South Eastern Health and Social Care Trust.

¹⁸ Powell, A. (2002). *Taking responsibility: good practice guidelines for services - adults with Asperger syndrome*. London: The National Autistic Society

¹⁹ *Asperger's syndrome and High Functioning Autism Pilot Project Evaluation* was conducted by Professor Noel Sheehy, Queens University Belfast, in October 2004.

The support that adults with autism say they need

Autism affects different people in different ways and this spectrum of needs must be met by a full spectrum of provision.

Many adults with autism require intensive 24-hour support, but even adults with high-functioning autism or Asperger syndrome, who appear to be very able, can struggle with daily living and are likely to need some level of assistance. Their very real abilities in certain areas can mask some very real needs and, without the support of professionals who have an understanding of autism, the needs of these adults can go unrecognised. All too often they find themselves invisible to local services.

In Figure 1, adults with autism identify several areas where they need support in order to live independently. These areas range from managing money and dealing with post, to preparing a meal and personal care.

The need for support in order to live more independently is similarly highlighted by parents and carers of adults with autism. When asked what support would enable the adult they care for to live independently, 40% said that their son or daughter would require 24-hour support (see Figure 2).

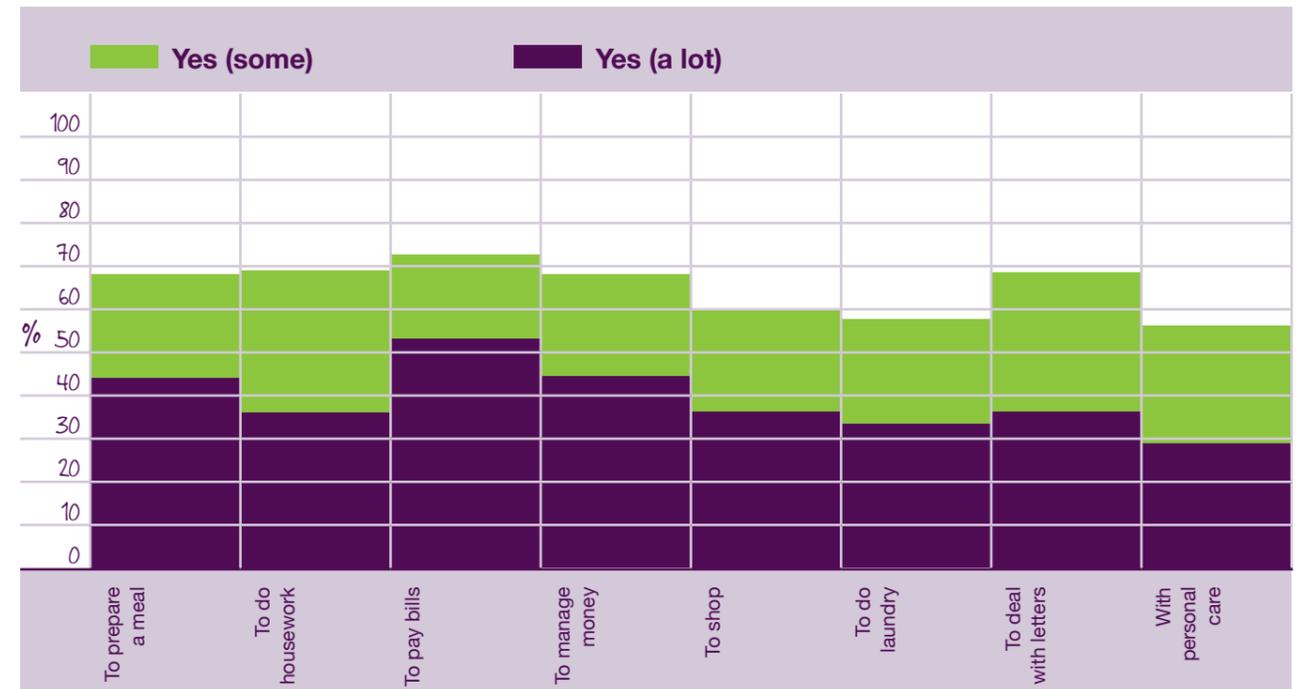


Figure 1 : The support adults with autism say they need

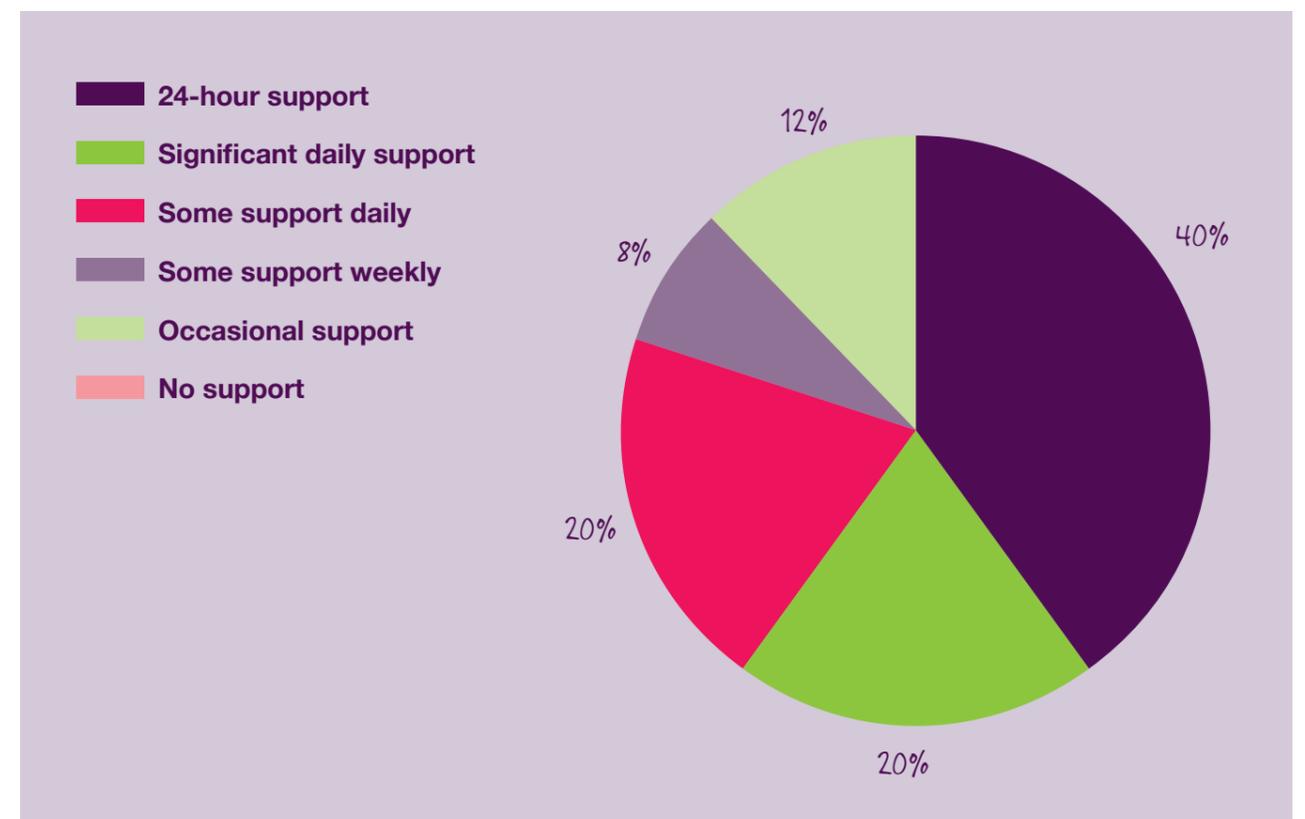


Figure 2 : What support would your son or daughter need to live independently?



Failure to meet real needs

Through our survey, adults with autism and their families and carers have identified the need for a variety of different supports at a range of different levels. However, there is frequently a large disparity between the support that adults would like to receive and the support they actually get. In particular, adults with autism tell us that there is a real need for preventative services; in other words, those services which are often less intensive in nature but which can prevent needs from increasing over the long term.

The preventative services which adults with autism would most like to receive are social support services, such as social groups and social skills training.

- > 46% of adults with autism in our survey would like to be involved in social groups, but only 19% are currently members of such groups.



- > 42% of adults with autism in our survey would like to receive social skills support but only 17% receive it.

Social support is also identified by parents and carers as the service most needed by the adults they care for. In our survey, the top three supports highlighted by parents and carers as being beneficial for their son or daughter are social groups (68%) befriending (52%) and social skills training (48%).

The need for social supports applies to people across the spectrum, including those with an accompanying learning disability. But there is evidently a shortage in the provision of this preventative support, even though it would help to prevent their needs from escalating.

Social support might be viewed by some people as being low-level in nature. While this may be true in relation to the relative cost and time spent in providing it, it is not low-level in terms of the impact it has on the lives of adults with autism – it is a lifeline.

Involving adults with autism in decisions which affect them

Following the recent Independent Review, there is now a real potential for the development of new services for adults with autism in Northern Ireland. But it is imperative that the views of adults with autism and their families and carers are taken into account when developing these services.

"It would be great getting the professionals to ask what we want or what we feel our children or young adults need. I think they just provide this service and say 'right you are, that's what you are looking for' – but I think we need to be asked what we really do need."

Parent

Conclusion

Our survey clearly highlights the gaps between what people know about autism and what daily life is like for those living with the condition. We all need to *think differently about autism* so that people with autism get a chance to make the most of their lives. And we need to act positively to address gaps in awareness, understanding, opportunity and support.

We have seen how easily adults with autism can become invisible to their local Health and Social Care Trusts and to decision-makers. The lack of information about the number of adults with autism in Northern Ireland and the poorly-defined lines of responsibility for providing services mean that autism simply does not get the priority it deserves.

Adults with autism are invisible to local services

Local Health and Social Care Trusts are unaware of the number of adults with autism in their area. This means that many adults with autism who are desperate for support are invisible to those agencies that have a duty to support them.

Adults with autism are misunderstood

A lack of understanding of autism among many professionals means that adults with autism often find it impossible to access support. Without a proper understanding of autism and how it affects each individual, health and social care staff cannot effectively assess the needs of, nor provide services for, adults with autism. The gap which exists between learning disability and mental health services further adds to the difficulties which many adults with autism face in securing the support that they need. No one has a clear responsibility for providing that support – this is a failing that leaves many people totally excluded from vital service provision.

Adults with autism are left to struggle though life

The recent Independent Review into Autism Services headed by Lord Maginnis identified an almost complete absence of services for adults with autism in Northern Ireland. There is an urgent need for this situation to be remedied. The right support at the right time can have an extremely positive impact on adults with autism, but this support needs to be autism-specific and appropriate to individual needs.

Action is needed to improve the lives of adults with autism

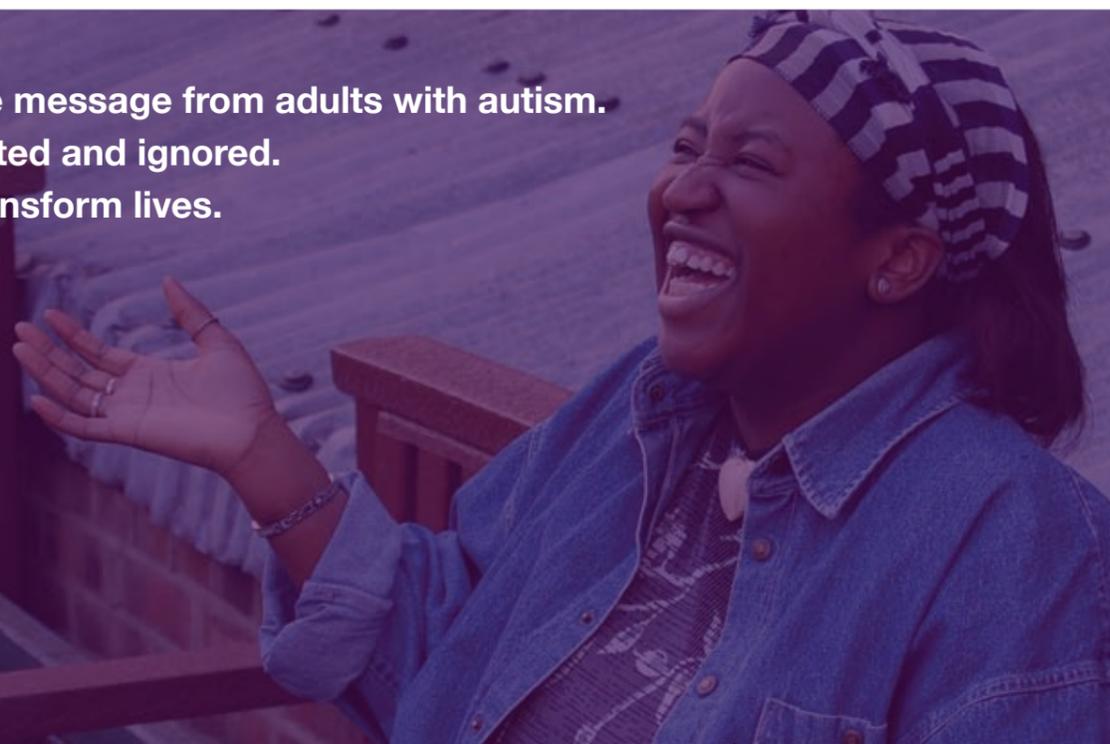
While the review itself and the subsequent ASD Strategic Action Plan is a welcome development, its recommendations will never be realised without appropriate funding and resources. **The Northern Ireland Assembly should ensure that the ASD Strategic Action Plan meets the needs of adults with autism. The plan should be fit for purpose to ensure that:**

- > local Health and Social Care Trusts record the number of adults with autism in their area
- > there is a named professional responsible for diagnosing adults with autism in each Trust area
- > Health and Social Care Trusts establish a clear route to enable adults with Asperger syndrome or high-functioning autism to access assessment and support
- > health professionals who are in regular contact with adults with autism are properly trained
- > adults with autism and their families and carers are involved in the development of services
- > new autism-specific services are developed for adults, families and carers.

The Northern Ireland Assembly should also ensure that there are clear accountability mechanisms in place to monitor the implementation of the ASD Strategic Action Plan. The plan should:

- > have clear targets that are time-specific and meet the needs of adults with autism
- > have adequate ring-fenced funding to ensure its delivery
- > be subject to an annual review by the Health, Social Services and Public Safety Committee to ensure that targets are met and consistent progress is made across all Trusts.

I Exist is the message from adults with autism.
Most are isolated and ignored.
Think. Act. Transform lives.



Methodology

The statistics in this report result from research undertaken in 2008. 47 respondents filled in questionnaires and 500 people were surveyed as part of the public attitudes survey. The purpose of this research was to provide a snapshot of what life is like for adults with autism and their families and carers in Northern Ireland.

Questionnaire for adults with autism

A questionnaire was produced for adults with autism (aged 18 and over) and their families and carers. There were three sections to the questionnaire.

The first section was a short section that asked for details about the person with autism. These details included the age and gender of the person with autism: 73% of the people to which the responses referred were male and 27% female; 51% were between 18-24 years of age, 23% were between 25-39, 23% between 40-64 and 2% were aged 65 or over.

The second section was the longest in the questionnaire and asked about the experiences of adults with autism. This was completed by adults with autism, and in some cases help was provided by their parents or carers.

The third section asked parents and carers about their own experiences and their views on the experiences of their son or daughter.

The figures in this report are based on the number of respondents who answered each question in the survey. All 'parent' quotes are from parents of adults with autism.

In-depth interviews with Health and Social Care Trusts

In-depth interviews were conducted with the five local Health and Social Care Trusts in Northern Ireland. These are the Northern, Southern, Western, Belfast and South and East Health and Social Care Trusts.

Public attitudes survey in Northern Ireland

The public attitudes survey was carried out by GfK in August 2008 and was based on a representative sample of all people aged 16 and over living in Northern Ireland.

Case studies of adults with autism

The case studies are based on four in-depth interviews with adults with autism. These interviews were conducted with adults from across the autism spectrum and represent their circumstances at the time the interviews were conducted in 2008.

Glossary of terms

Befriending: a befriender is a trained volunteer who spends time with an individual on a regular basis to enable them to take part in social activities.

Direct Payments: a scheme through which local Health and Social Care Trusts give money to people to buy their own social care services so that they have more say in how their needs are met.

Health and Social Care Trusts: Health and Social Care Trusts have the overall responsibility for assessing health needs and providing health care within their geographical area. There are five Health and Social Care Trusts in Northern Ireland.

Northern Ireland Assembly: The Northern Ireland Assembly is the elected legislature of Northern Ireland. It has responsibility in many areas, including health and education.

Social groups: groups which enable adults with autism to meet and take part in social activities in a supported environment.

Social skills training: training which aims to improve an individual's ability to participate in social situations and interact with others.



Autism also affects adults
Most are isolated and ignored

Think. Act. Transform lives.

Over 17,000 people in Northern Ireland have autism.
Together with their families they make up over 68,000
people whose lives are touched by autism every single day.

Despite this, autism is still relatively unknown and
misunderstood. Which means that many of these two
million people get nothing like the level of help, support
and understanding they need.

Together, we are going to change this.

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