



Scottish Borders Autism Strategy

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Foreword

The Scottish Strategy for Autism was published in 2011 marking growing recognition that autism deserves an agenda in its own right. The development of the national strategy ensures progress will continue to be made in delivering quality services for individuals on the spectrum.

In response to the national agenda for autism, the Scottish Borders has developed a local strategy, to ensure the needs of individuals on the spectrum of all ages living in the Borders will be acknowledged, and addressed.

A group of professionals from NHS, Education, Social Work and the Third Sector, including parents and carers, have been meeting to develop this draft strategy. The group has discussed the priority areas of need, identified through the Autism Mapping Project, conducted in 2013, and through professional and personal contributions.

The core part of the strategy is split into seven main sections addressing each of the priority areas, each linked to a section in the action plan. The thematic sections detail local context, a strategic overview and findings from our engagement process (including the mapping project).

Seven priority areas have been identified for action locally:

- 1. Autism awareness and training** – Improving public and professional awareness and understanding of autism;
- 2. Diagnosis** – Good-quality early diagnosis and intervention for both children and adults;
- 3. Getting the right services at the right time, for adults with autism and no learning disability** – Addressing the eligibility criteria and improving access to appropriate support;
- 4. Purposeful occupational activities** – Finding the right opportunities to pursue individual interests and employment;
- 5. Social support and opportunities** – Opportunities to develop social skills and accessing a range of social opportunities;

6. Improving access and provision of housing – Addressing the barriers to finding, securing and maintaining individual housing needs;

7. Ensuring inclusion for people with autism and their families – People will have their voices heard and acknowledged by professionals.

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It is our vision that people with autism and their families, living in the Scottish Borders, feel accepted and valued by their community, and have equal access to knowledgeable services, when they need them, so that they are able to live the lives they choose.

Our Vision

The purpose of this strategy is to help us achieve this vision. The strategy will set the tone and direction for improving outcomes for individuals on the autism spectrum and their families, across the lifespan, by detailing where we want to be in the next 10 years.

The delivery plan will describe some of the actions that need to happen over the next 2, 5 and 10 years to get us to where we want to be.

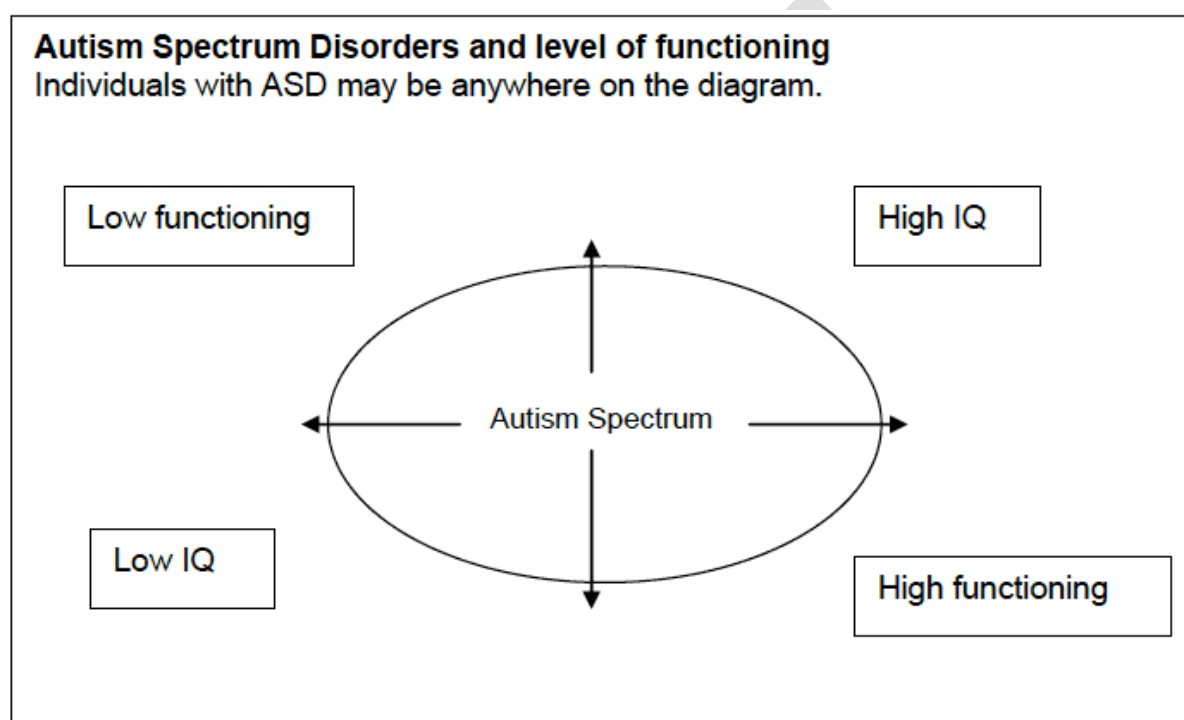
The services and support referenced throughout this strategy and plan will be provided by the Scottish Borders Council, NHS Borders and our partners (*).

Question 1 – Do you agree with our vision?

What is Autism?

Autism is a complex, lifelong developmental disorder and is sometimes referred to as Autism Spectrum Disorder (ASD) or Autism Spectrum Condition (ASC).

Autism is a spectrum condition incorporating a wide range of characteristics that some people may or may not share, which can make some aspects of life difficult. Therefore, each individual on the spectrum is unique and may or may not require support, in various forms, to live an independent life.



Characteristics that are common to all individuals on the spectrum, however, include:

- **Social communication (i.e. use of verbal and non-verbal language)**
- **Social interaction**
- **Social imagination/flexibility of thought**

(Note, the American Psychiatric Association classification of autism has recently changed)

It is important to note that some individuals on the spectrum, but not all, will experience **over- or under-sensitivity to noise, textures, vision, smell, balance, taste and/or proprioception**, which can be the source of overwhelming stress and anxiety for the individual.

Use of language

The complex nature of the autism spectrum gives rise to a number of personal and professional perspectives, therefore it can be difficult to find a common language. However, it is important to note that we will adopt the language and terminology used within the National Autism Strategy; as such, we have tried to reflect the diversity of this community in a positive way.

Furthermore, we understand there is a need to be sensitive when using words like 'impairment' or 'disorder'. These words are recognised clinically and in a professional realm, however many people with autism do not accept these terms, instead preferring to stress that they have a different way of perceiving and engaging with the world.

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Why do we need an Autism Strategy for the Borders?

It is essential to understand that individuals with autism may think about, perceive and, therefore, understand others and the world around them differently from the general population.

'Never mind thinking outside the box, I just wish I could think inside the box'

(Person with autism)

It is also important to understand that no two people with autism are alike, therefore each individual's needs are unique and personal. Some people with autism may require a high level of support, on a daily basis, to help them with daily tasks, while others may only need a little support now and again to help them when they need it. Autism is a life-long condition, however people's needs change as they go through life.

Currently, individuals with autism may not find the services they need or find them difficult to access. As such, they may miss out on achieving the things they wish to achieve in life. This is unfair and can lead to a poor quality of life and subsequent mental health problems.

Responsibility for delivering successful services for people with autism is widespread - there is not a singular agency that is responsible for providing services for people with autism. People with autism may be in contact with both specialist and mainstream services. This strategy will aim to make a link between specialist and mainstream services, to support coordinated responsibility and improve access to mainstream services.

We need an autism strategy in order to improve the quality of life for individuals with autism.

An example of feedback in relation to where we want to be:

We can do this through educating the population about autism and by making adjustments to our existing services to remove the barriers individuals with autism face and by further investing in and developing services across all the sectors which provide valuable services.

The National Picture of Autism

There are a number of key national drivers that are relevant to achieving the aims of our autism strategy. They impact upon the planning, commissioning and the delivery of a wide range of services. It is important for us to understand and incorporate these national initiatives, to ensure our local autism strategy reflects the strategic direction of the Scottish Government.

The Scottish Strategy for Autism (2011)

'Autism is a national priority'

Scottish Strategy for Autism, 2011

In 2011, the Scottish Strategy for Autism was published, declaring autism as a 'national priority', following a decade of autism specific initiatives (see Appendix A). The national strategy aims to harness these initiatives and address the entire autism spectrum and the whole lifespan of people living with ASD in Scotland, over the next ten years.

Considerable efforts have been made to improve diagnosis and assessment, to create consistent service standards, to match resources to need and to underpin this with appropriate research and training opportunities.

The vision of the Scottish Strategy for Autism is that **'individuals on the autism spectrum are respected, accepted and valued by their communities and have confidence in services to treat them fairly so that they are able to have meaningful and satisfying lives.'**

The Scottish Government also agreed the following values that underpin the National strategy:

Dignity

Privacy

Choice

Safety

Realising potential

Equality and diversity

The Scottish Government describe 10 ways in which good services for people with autism should be developed:

1. A local strategy
2. Access to training and development
3. Easy access to useful and practical information about autism
4. An autism training plan
5. A process for data collection which improves the reporting of how many people with autism are receiving services and informs the planning of these services
6. A multi-agency care pathway for assessment, diagnosis and intervention
7. A way to get feedback to inform service improvement and encourage engagement
8. A multi-agency coordinated focus on meeting the needs of people with autism
9. Clear transitions at each important life stage
10. A self-evaluation framework to ensure best practice implementation and monitoring.

26 recommendations are listed in the Scottish strategy, which, in summary, say that:

- The Scottish Government will provide strategic leadership and create a strategic vision for the development of services and support for those with or affected by autism
- Resources will be effectively targeted with the aim of improving people's lives
- People with autism and their families should be involved in decision making
- Cross agency working will be developed
- Adults should be able to get a diagnosis and support following a diagnosis
- People with autism should be supported to gain employment

The Ten Year Plan

To ensure the Scottish Government address their recommendations by the time the strategy concludes, they have set goals over 2, 5 and 10 year time periods. This is shown below and will guide the timeline of our local delivery plan.

Foundations; 2 year goals	Whole Life Journey; 5 year goals	Holistic, Personalised Approaches; 10 year goals
<p>1. Access to mainstream services where these are appropriate to meet individual needs.</p> <p>2. Access to services which understand and are able to meet the needs of people specifically related to their autism.</p> <p>3. Removal of short term barriers such as unaddressed diagnoses and delayed intervention.</p> <p>4. Access to appropriate post-diagnostic support for individuals and families (particularly when there has been a late diagnosis).</p> <p>5. Implementation of existing commissioning guidelines by local authorities, the NHS, and other relevant service providers.</p>	<p>1. Integrated service provision across the lifespan to address the multi-dimensional aspects of autism.</p> <p>2. People with ASD have access to appropriate transition planning across the lifespan.</p> <p>3. Consistent adoption of good practice guidance in key areas of education, health and social care across local authorities.</p> <p>4. Capacity and awareness-building in mainstream services to ensure people are met with recognition and understanding of autism.</p>	<p>1. Meaningful partnership between central and local government and the independent sector.</p> <p>2. Creative and collaborative use of service budgets to meet individual need (irrespective of what entry route to the system is).</p> <p>3. Access to appropriate assessment of needs throughout life.</p> <p>4. Access to consistent levels of appropriate support across the lifespan including into older age.</p>

'Autism impacts on the whole life experience of people and their families; they need to be supported by a wide range of services such as social care, education, housing, employment and other community based services. A holistic, joined up approach is necessary.'

Scottish Strategy for Autism, 2011

Other national drivers that have influenced the development of our strategy and our action plan:

Social Care (Self-directed support) (Scotland) Act 2013

Self-directed support (SDS) is a term that describes the ways in which individuals and families can have informed choice about how their support is provided to them. It is most commonly used in the delivery of social care and support, but it can cover a much wider range of services.

SDS gives people control over an individual budget and allows them to choose how it is spent on support which meets their agreed health and social care outcomes.

SDS includes a number of options for getting support. The person's individual budget can be:

- Taken as a Direct Payment (a cash payment);
- Allocated to a provider the individual chooses. The council or funding body holds the budget but the person is in charge of how it is spent (this is sometimes called an individual service fund);
- Or the individual can choose a council arranged service;
- Or the individual can choose a mix of these options for different types of support.

SDS allows people with autism and their carers to choose the support that is right for them and enables them to access a much greater range of supports to suit their needs and help them to achieve the outcomes that are important to them.

Public Bodies (Joint Working) (Scotland) Bill 2013

This Bill seeks to achieve greater integration between health and social care services in order to improve outcomes for individuals and to improve the efficiency of services. There is no single definition of what constitutes integrated care, but the term is commonly used to refer to the joined up delivery of health and social care services. Integration is viewed as a way of tackling a number of problems such as unscheduled admissions to acute care, delayed discharges, budgetary battles between bodies, delays in accessing care and duplication of efforts. It is also seen as a way of 'shifting the balance of care', from the expensive acute sector, to care in less expensive community settings.

The concept of integration is not new to Scotland and the Bill is the latest in a line of attempts to achieve integrated care. Previous attempts have included the Joint Futures Agenda and the creation of Community Health Partnerships. The Bill proposes to require health boards and local authorities to create an integration plan for the local authority area. This will be required for adult services, but other services may also be included. The integration plan will be required to detail which model of integration had been chosen and also sets out principles that should guide the creation of integration plans.

Integration proposals have the potential to greatly improve the way services are delivered for people with autism through a more joined up approach from diagnosis and treatment through to on-going support.

Mental Health Strategy for Scotland 2011 - 2015

The Mental Health Strategy for Scotland indicates the priority placed on mental health by the Scottish Government and covers 14 high level outcomes. These include:

- People and communities protecting their mental well-being;
- People having a better understanding of their mental health;
- Care and treatment focuses on the whole person; and
- Professionals understanding the role of families and carers.

This single mental health strategy will encompass:

- Mental health improvement work;
- Mental illness prevention work; and
- Work to improve mental health services in general.

This will be a key influence in the coming years on the delivery of autism services and will help shape the services to include mental health improvement and the prevention of mental health problems.

The Keys to Life: Improving quality of life for people with learning disabilities (2013)

The Scottish Government published 'The Keys to Life' in 2013, as a renewed and refreshed strategy for people with learning disabilities, following the publication of 'The Same as You?' in 2000.

The Keys to Life sets out human-rights based principles, with aim of continuing a cultural shift towards meaningful change for people with learning disabilities, as well as continuing to improve quality of life for people with learning disabilities.

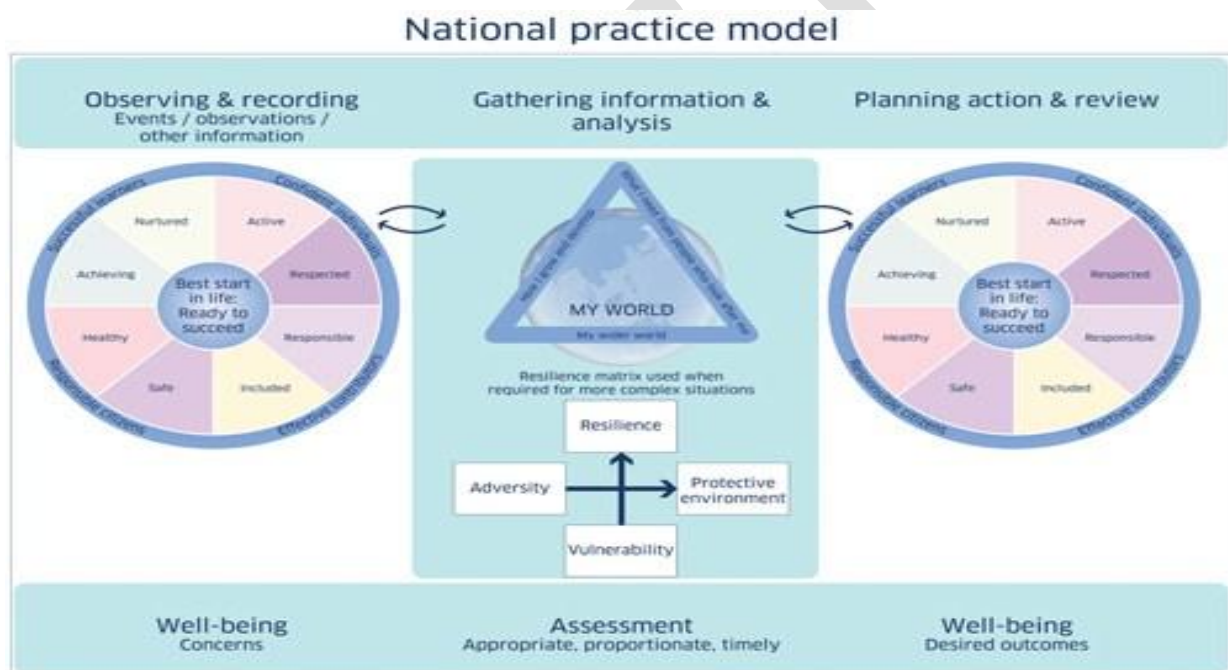
The strategy includes over 50 recommendations, embedded in 7 broad sections, including:

- Health;
- Independent living;

- Shifting the culture and keeping safe;
- Breaking the stereotypes;
- People with profound and multiple learning disabilities;
- Criminal justice;
- Complex care.

Getting It Right for Every Child (GIRFEC)

The National Practice model is a dynamic and evolving process of assessment, analysis and review and a way to identify outcomes and solutions for individual children or young people. It allows practitioners to meet the *Getting it right for every child* core values and principles by being **appropriate, proportionate and timely** - (*The Scottish Government*)



GIRFEC in the context of the Scottish Borders Autism Strategy

The values and principles of GIRFEC will be recognised within the implementation of the priority areas identified in the Scottish Borders autism strategy. The National practice model will be used as a guide to implementing, monitoring and evaluating the actions from the strategy which relate to improving opportunities and experiences for children and young people living in the Scottish Borders. The local strategy also acknowledges the importance of practice which currently demonstrates how the GIRFEC framework is used within the region and the impact this has on outcomes for children and young people.

A strategy for the Borders

Our strategy for the Borders will reflect and incorporate these priorities and national drivers; it is the responsibility of everyone involved to be mindful of these at the point of service planning and delivery.

The Local Picture

Locally, there are a number of policies in place which will inform the development and delivery of our autism strategy for example the local housing strategy and children and young people's strategy. Also, we can learn from previous autism-specific projects that have been available locally, in order to help us identify what is working well, what needs improved and what is missing, for people with autism in the Borders.

A description of these and their relevance are provided below; a link to each document can be found in Appendix B.

Local Policy

The Single Outcome Agreement (SOA)

Scottish Borders Council and their community planning partners are responsible for working for the benefit of people living in the Borders. The outcomes of this partnership are published in the [Single Outcome Agreement](#) – a document agreed between the council, its partners and the Scottish Government.

“By 2023, quality of life will have improved for those who are currently living within our most deprived communities, through a stronger economy and through targeted partnership action”

Scottish Borders Single Outcome Agreement

The current SOA focuses on the key priority improvement areas for the Borders and highlights the areas where concerted partnership effort is required. These priority outcomes

then have Performance Indicators. By monitoring things on a regular basis, it will be possible to see if the work being done by public sector partners is having a positive impact.

Local policy and strategy development needs to ensure that services for people with autism are inclusive and meet all equality and diversity strands.

Previous local Autism specific projects

The Scottish Borders Autistic Spectrum Disorder Coordinator Project Report (2006)

From 2005 to 2006, the Scottish Executive (Scottish Government) funded the Adult Autism Spectrum Disorder (ASD) Co-ordinator post. The remit of the co-ordinator was firstly to be a 'change agent' in the lives of adults with ASD, their families, friends, carers and the services that support them in the Scottish Borders. Second, the co-ordinator was responsible to help plan, in partnership with NHS Borders and Scottish Borders Council, services for adults with ASD and their families.

There were 8 key areas for action:

- Driving forward the agenda for adults with ASD;
- Audit the numbers of adults with ASD in the Scottish Borders;
- Promote the development of an ASD database;
- Audit services and provision available to adults with ASD;
- Create ASD information base;
- Promote the use of a multi-agency care pathway for adults with ASD and the use of Person-Centred Planning;
- Raise awareness of ASD in the Scottish Borders;
- Promote the review of adults with ASD who are placed outwith the Scottish Borders.

The Autism Co-ordinator project was the beginning of a number of positive initiatives and was key in raising the profile of adults with autism living in the Scottish Borders.

National Autism Mapping Project (2013)

As part of the National strategy launch, the Scottish Government announced £13.4 million of additional investment to be distributed over 4 years, some of which would be dedicated to mapping out autism services and improving coordination of these services.

Coinciding with a one-off investment of £35k for each local authority in Scotland to develop their own local Autism Action Plans, **the aim of the Autism Mapping Project ('the project') was to:**

- consult with people with autism, their families and carers, service providers and local agencies;
- map out existing autism service provision in all local areas in order to build up a local and national picture;
- identify priority areas for action that reflected local need;
- work collaboratively with local partnerships, councils, NHS, criminal justice, third sector organisations and other relevant public bodies;
- provide local authorities with a 'Service Map' of their area, to inform their Autism Action Plans.

A national report was developed which provides a 'snapshot' of autism services across Scotland, setting out the key issues identified by people with autism and their carers, and provides an overview of how services are meeting their needs or where there may be gaps in services (the national report can be found at: <http://www.autismstrategyscotland.org.uk/news/autism-mapping-project-report.html>).

The local service map was compiled using evidence collected in the Scottish Borders. We asked people with autism, parents & carers and professionals for their views on what is working well, what needs to be improved and for any gaps in service provision in the local area (the Scottish Borders Service Map can be found at: <http://onlineborders.org.uk/community/asdborders>).

The local service map was used to help us identify the priority areas of need for development. We organised two focus groups for parents & carers, two focus groups for people with autism and one focus group for professionals. We also used a number of questionnaires to collect individual and organisational responses. A breakdown of the respondents is shown below (please refer to the full report for more information):

Focus Groups	No. of participants	Questionnaire	No. of participants
Multi-agency professionals	17	Multi-agency professionals	3
Service providers	N/A	Service providers	8
Parents & Carers	17	Parents & Carers	8
People with autism	7	People with autism	3

The data collected from the workshops and the questionnaires was analysed to create a number of key themes across all key stakeholder groups.

The key themes from each stakeholder group (people with autism, parents & carers, and professionals) were compared and **the priorities that matched became our initial priorities, for further engagement.**

Autism, in Numbers

National estimated prevalence

The prevalence estimates in the Public Health Institute of Scotland (PHIS) ASD Needs Assessment Report (2001) suggested 60 in every 10,000 people have autism. However, the Scottish Strategy for Autism (2011) reports that more recent studies estimate the prevalence of autism in children and adults in Scotland to be around 1 in 100.

Autism is diagnosed more commonly in males than females, at a ratio of approximately 4:1, although this varies across the spectrum.

Local estimated prevalence and data

According to Scotland's 2011 Census, the population of the Scottish Borders is 113,870. Using the estimated prevalence of 90 per 10,000, as detailed in the Scottish Strategy for Autism, there would be an estimated 1,025 people with autism living in the Scottish Borders.

Adults

The Scottish Consortium for Learning Disabilities (SCLD, eSay 2012) reports that there are 3,385 adults in Scotland with autism spectrum disorder who are known to local authorities; most of these adults have a learning disability.

SCLD reports that in the Scottish Borders, there are 107 adults with an autism diagnosis. This includes: 98 people with a diagnosis of 'Classic Autism'; and 9 people with a diagnosis of 'Asperger's Syndrome'.

Children and Young people

The Additional Support for Learning and Young Carers Report for Parliament (2013) reports that in the Scottish Borders there are 1,757 children and young people in education with additional support needs. The report highlights that 76 of these individuals have autism in the Scottish Borders.

People with autism known to statutory services

We asked Scottish Borders Council and NHS Borders to collate the number of people with a diagnosis of autism (including Asperger Syndrome) known to their services.

SBC Social Work data

The table below shows the number of people in contact with social work services. Please note:

- The people represented below may or may not have a formal, clinical diagnosis of autism or Asperger Syndrome;
- Some people with autism who have had contact with social work services may not appear in the table, due to recording methods;
- Some people with a diagnosis of autism or Asperger Syndrome are recorded in the NHS data, but have not been in contact with SBC Social Work, so will not be represented in the table below;
- These figures represent a snapshot of data currently held

	Autism			Asperger Syndrome			Grand Total
	Female	Male	Total	Female	Male	Total	
Child under 16	1	27	28	0	2	2	30
Adult 16+	21	68	87	2	9	11	98
Grand Total	22	95	117	2	11	13	130

NHS Borders data

Children

The Child and Adolescent Mental Health Service provides local coverage for autism assessments in the Borders, for children up to the age of 16 years old. From 2009 to 2014, there are 114 children on their database, 60 of whom have a diagnosis of ASD.

Adults

The NHS Borders data supplied gives the number of people with autism who have had an inpatient episode, or have been seen by the Mental Health Service, or the Joint Learning Disability Service. Data on wider prevalence is not currently available.

Team	Total
Joint LD Service	29
Adult Mental Health Teams	40
Total	69

Wherever possible, we have tried to avoid duplication of numbers within the data presented; however, due to the recording methods used, a degree of duplication may exist.

For information regarding spend across agencies, please refer to Appendix B.

Towards an Autism Strategy for the Borders

Step 1: Identifying our priorities

A strategic group has been meeting since June 2012 to identify areas of need and develop action points to address them. Members of the strategic group include representatives from NHS Borders, Scottish Borders council, Education (including further education), learning disability services, the voluntary sector, a carer organisation and parents of people with autism.

We used the local Borders Service Map from the Autism Mapping Project (for a full description, see 'Local Autism Specific Projects' above) to help us identify our initial priorities for further development.

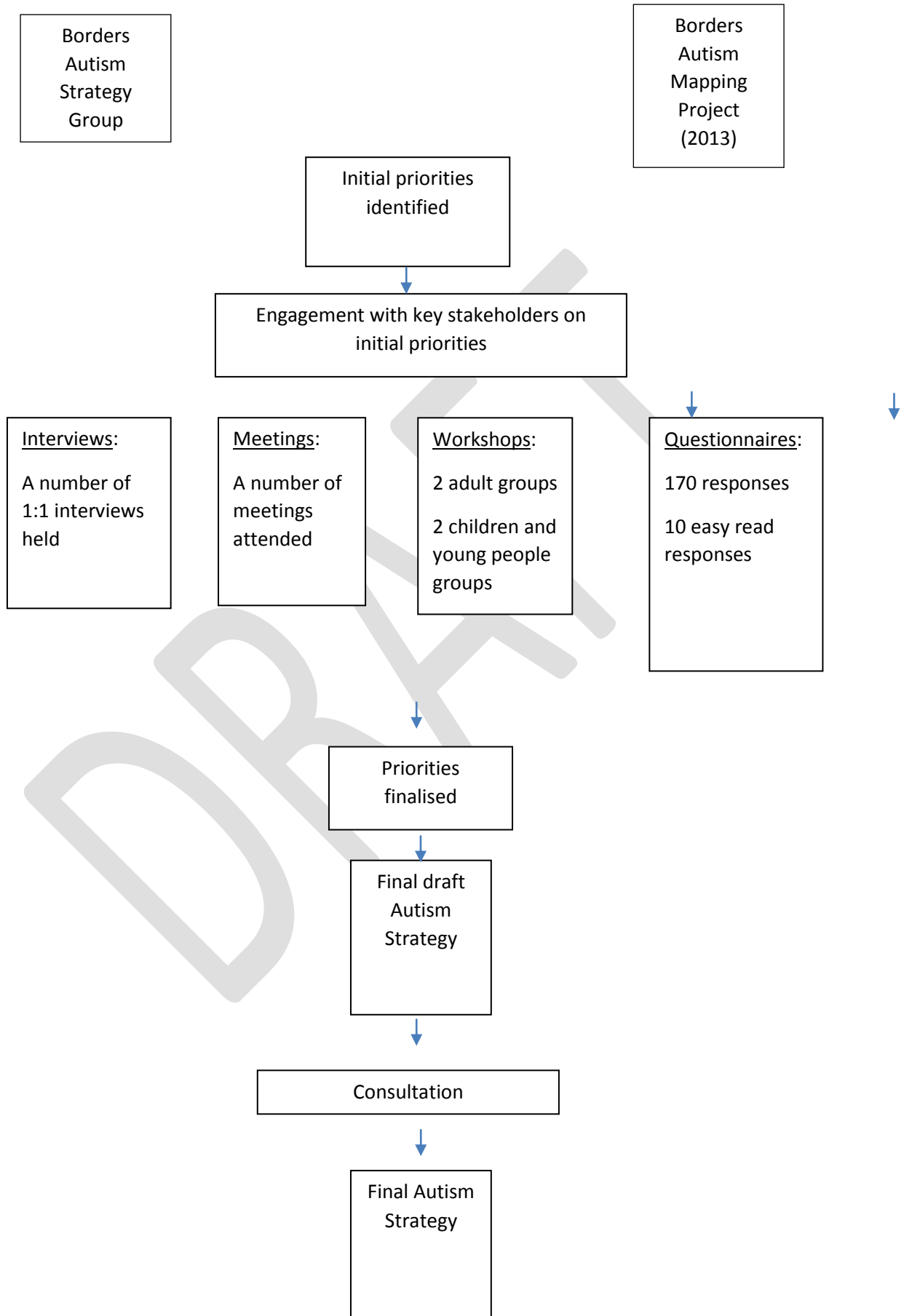
Step 2: Finding out what people think of our priorities

Over a 6 month period from November 2013 to March 2014, we engaged with a range of key stakeholders, including senior managers, practitioners, clinicians, parents and carers, and people with autism. Using a variety of methods, we asked people if they agreed with our priorities and for their opinions and personal experiences related to them.

The statements detailed under each priority area in the following pages of the strategy have been drawn from all stages of the engagement process, including our questionnaire, workshops, meetings and interviews - as shown in the figure below.

The feedback was summarised and the main themes are included as part of the narrative running throughout the strategy.

The engagement process and participation:



What is Working Well?

In order for our strategy to be successful and improve the lives of people with autism, we must learn from, and continue to build upon, the vast amount of good work that already exists here in the Borders.

Engagement with people with autism, their carers and families and professionals, during both the mapping project and through the development of the strategy, highlighted a number of examples of effective autism practice.

Effective practice example 1: Co-ordinated Support in Education

A number of positive experiences were reported within primary education. An Individualised Education Programme/plan (IEP) is key in coordinating various strands of support: inputs from Speech and Language therapy and Occupational therapy have a significant impact on the educational experience of the child. Additional adjustments made by a teacher who has attended autism awareness training were also highly beneficial. Positive approaches include ear defenders, having a quiet place to go, and supporting the child as an individual, rather than a diagnosis. Good practice was also evident in the communication between professionals around the IEP.

Effective practice example 2: Transition Planning for Child in Primary Education

Spectrum Support, education outreach team ensure that a dedicated transitions teacher is allocated to each P6 pupil with autism at the very start of the primary/secondary transfer process. The teacher gets to know the child in their familiar primary setting before introducing them to their local secondary school where they will continue to support them throughout their secondary career. The support includes: supported visits; developing pupil profiles; transition booklets; working with parents; supporting independent travel to their new school; and training of school staff in the receiving school prior to them starting. This ensures children and their parents/carers are well-informed about the new school, have a known face to continue support in the new setting and school staff have been prepared for their new pupils.

Other services reported as working well:

- The Learning Disability services available in the Borders are multi-agency and effective, especially for children and young people;
- Home visiting teachers;
- The voluntary sector consistently received positive feedback;
- The special needs dental service in Galashiels was frequently reported as working well.

Priority Areas Identified for the Borders

The Scottish Borders Council, NHS Borders and its partners recognise that the needs of people with autism are diverse, and are committed to ensuring change to improve people's quality of life, and to help people achieve what they want to in life.

It is our vision that people with autism, living in the Scottish Borders, feel accepted and valued by their community, and have equal access to understanding and knowledgeable services, when they need them, so that they are able to live the lives they choose.

We will work together towards achieving our vision, over the next 10 years.

We have engaged with key stakeholder groups and asked them what they think is working well, what needs to improve and what gaps exist for people with autism living in the Borders. This information has helped us identify the foundations of good practice to build upon, and other areas of life that we will aim to develop.

The themes for further development were cross referenced between each stakeholder group and we identified 7 specific, consistently referenced priorities.

The following sections will detail what people have said about each theme, and the call out boxes show direct quotes from questionnaire respondents. The resulting actions for change can be found in the corresponding thematic section in the delivery plan:

The 7 Priority Areas

- 1. Autism awareness and training** - Improving public and professional awareness and understanding of autism;
- 2. Diagnosis** - Good-quality, early diagnosis and intervention for both children and adults;
- 3. Getting the right services at the right time, for adults with autism and no learning disability** - Addressing the eligibility criteria and improving access to appropriate support;
- 4. Purposeful occupational activities** - Finding the right opportunities to pursue individual interests and employment;
- 5. Social support and opportunities** - Opportunities to develop social skills and accessing a range of social opportunities;
- 6. Improving access and provision of housing** - Addressing the barriers to finding, securing and maintaining individual housing needs;
- 7. Ensuring inclusion for people with autism and their families** - People will have their voices heard and acknowledged by professionals.

1. Autism awareness and training

‘This is very important for a number of reasons; early intervention, management of the condition, and understanding how, very often, people on the spectrum see and understand the world in a very different way from someone who is not on the spectrum’

Improving public and professional awareness and understanding of autism

**Questionnaire
respondent**

Feedback Received Summarised

Over 90% of the respondents to our questionnaire agreed that autism awareness and training should be a priority for further development in the Borders. People stressed the importance of increasing autism awareness and understanding in order to make a significant difference to the life of people with autism.

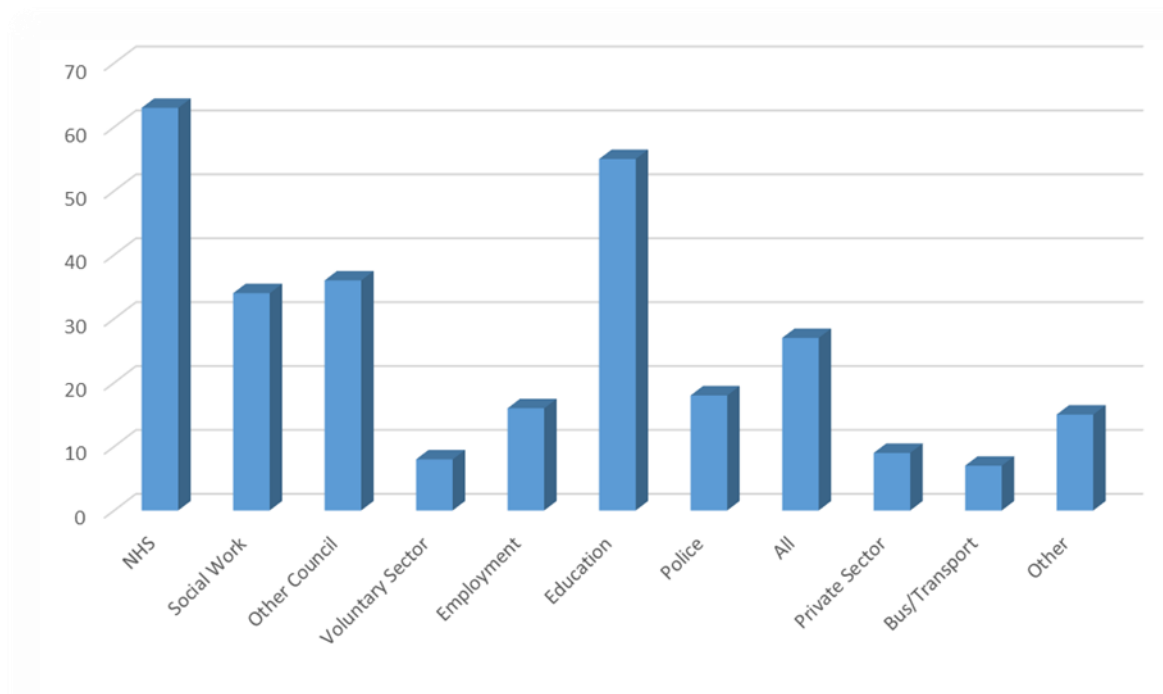
Improved awareness and understanding of autism can improve access to key, mainstream services. There is evidence which shows that basic awareness training on autism can significantly improve people’s ability to communicate with people with autism. Developing a better understanding of autism will also address commonly held misconceptions in society, which can be potentially harmful.

Autism is a complex condition and, for some people, it may not seem obvious that they have a diagnosis – some people refer to autism as an ‘invisible condition’. People commented that autism awareness initiatives should specifically include information about Asperger Syndrome and the difficulties somebody may experience in their daily life.

Through our engagement, people highlighted the need for society in general, and both mainstream and specialist services to develop a better understanding of autism, for people with autism to lead fulfilling lives. There is a lot of good, individual work that exists already to increase autism awareness, however people are not always aware of it and it can often be inconsistent. People with autism said there needs to be a shared understanding of autism across both NHS services and Scottish Borders Council.

“There is a lot of good individual work, however there needs to be a cohesive approach used”

The graph below shows services people specifically named, in need of further autism training. The responses were grouped into relevant agencies – for the full list of these services, please see the Appendix .



Where we want to be

The National Training Framework for Autistic Spectrum Disorders provides a scaffold to support individuals and services to find pathways through training and to select from the variety of study programmes available - from informal, community-based or on-the-job training, through to award-bearing, credit-rated courses of formal learning. This should be incorporated in the Borders, to allow the identification of training needs for the individual or service.

We want the general population to recognise autism and Asperger Syndrome. This begins with a broad approach to developing awareness in society, represented in the first tier of the triangle figure below.

In order to ensure services meet the needs of people with autism, service providers need to be targeted with an in-depth level of autism training. This would apply to some of the services shown in the graph above and is represented as the middle tier of the triangle figure.

The top tier of the triangle represents the highest level of training for specialist professionals working in the autism field. In order for services to be equipped with the most up to date information, specialist practitioners need to continue to receive this level of training.



Question 2: Do you agree with the strategic direction of this priority area?

2. Diagnosis

'The earlier autism can be diagnosed and assessed, the better the quality of life for the individual'

Good-quality, early diagnosis and intervention for both children and adults

Questionnaire
respondent

Feedback Received Summarised

Over 95% of questionnaire respondents support diagnosis as an area for future development.

Going through an assessment for autism and receiving (or not receiving) a diagnosis can be both a positive personal experience and a stressful, emotive experience. We know that having a diagnosis of autism can be the first step towards self-understanding and can be the key to accessing the right support.

Early diagnosis and intervention are reported as significantly improving outcomes for people with autism. However, feedback showed that some people had difficulty being referred for an autism assessment and others had to wait a long time for the assessment. In some cases, people were diagnosed much later in life after going through various other routes in mental health services.

"The earlier, the better"

Pre-diagnostic support

Feedback indicated some people are not sure of any existing pathways or routes to and through the diagnostic process and do not know where to look to find this information. Therefore, people are often not sure how to start going about obtaining an assessment for autism. This often led to people carving out their own path to an autism assessment, which prolonged the process greatly. Some feedback showed that for adults without a learning disability, the route to diagnosis is especially not clear.

"Clear guidelines should be available as to how to access an assessment, what it will involve and how long the process takes"

People thought that regular autism training for frontline staff across a number of agencies (including health visitors, community based services, nursery/primary/secondary teachers, and adult service practitioners) and the public in general, would help people recognise autism and direct people to the next action, towards an autism assessment. It was thought that this would allow for a quicker referral to the relevant diagnostic service.

The Assessment Process

Going through an assessment for autism can be very stressful for the individual and their family. It was reported that there is a lack of support during the assessment process. People said that information about the assessment and what to expect would be helpful in reducing stress and anxiety.

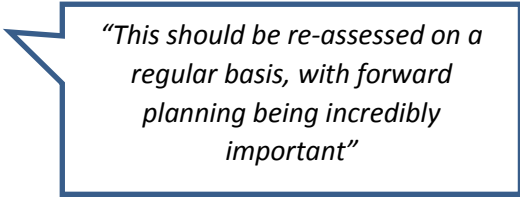
We have been told that for adults without a learning disability, the assessment process is very difficult and there is a need for a local service, dedicated to assessing this client group.

People also talked about the length of time the assessment takes to complete; some people thought it took too long and wanted to know the outcome quicker than is currently happening. Feedback from clinicians, however, indicates that the length of assessment is dependent on the complexity of the assessment and the number of professionals involved, due to the multi-disciplined nature of the assessment.

Post-Diagnostic support

People highlighted both short term and long term intervention as important. Key to both these timescales is information; people want information to be made available on various mediums, including websites, mobile phone apps, books and a list of key contacts and services in a directory. Access to appropriate services for the short term and long term planning was highlighted as important. Furthermore, people were not sure of any existing pathways which map out an individual's route from diagnosis to existing services. It was also felt that families should receive information for where they can find support.

Feedback included the need for regular reviews to occur, following a diagnosis, in order to plan out key life stages.



"This should be re-assessed on a regular basis, with forward planning being incredibly important"

Voluntary organisations were reported as being supportive and helpful following diagnosis; people are keen that the assessment service develops stronger links with existing support services, in the voluntary sector.

Where we want to be

We want people to have easy access to central information about the diagnostic process, including pathways, so they are clear about who to contact, what the assessment will involve and what will happen after the assessment; irrespective of whether or not they have an existing mental health condition or learning disability. This should be available in a variety of formats.

We want the assessment process to be completed to a high and consistent standard, in line with current clinical guidance. People should be informed about what to expect and be aware of the estimated time periods to complete the assessment.

We want people to have equal access to appropriate support following a diagnosis of autism, with information about the condition and about available services.

Question 3: Do you agree with the strategic direction of this priority area?

3. Getting the right services at the right time, for adults with autism and no learning disability

I feel there is a lack of support and services for people with autism and no learning disability. People assume if you are of high intelligence you do not require any support'

Addressing the eligibility criteria and improving access to appropriate support

**Questionnaire
respondent**

Feedback Received Summarised

Over 90% of respondents agreed that getting the right services at the right time, for adults with autism and no learning disability should be a priority for further development. This client group have a diagnosis of Asperger Syndrome (AS) or High-Functioning Autism (HFA).

The needs of this group of people can be intricate and complex; their needs can be difficult to identify through typical assessment and can be dependent on environmental factors.

People reported a gap in services for this client group; often, people with AS and HFA fall in between mental health services and learning disability services. Some people told us the needs of this client group are not fully understood and are not incorporated well in social work assessment tools as a result, which means they often miss out on the support they need.

We understand that people are not aware of existing services, available locally or how to access them; feedback indicated a lack of information also contributed to the feeling of a lack of services in the Borders.

"having a directory of services which is available to all, accessible and updated regularly"

People described a range of services that were required for this client group to work towards independent living, including: post-diagnostic support; employment support; benefits advice; befriending; social activities; housing; and further education support. The benefits of having an expert level of autism knowledge in these services was apparent through our engagement.

The geography of the Borders was raised as a potential barrier for finding a central location for services, which could cater for a number of rural towns.

Where we want to be

AS and HFA are sometimes referred to as a 'hidden' or 'invisible' condition. We want understanding of AS and HFA to improve greatly, so that the needs of this client group are accurately assessed and supported. We want people to know where to go to find information, that is accessible and up-to-date, and for people to know how to access services that are right for the individual.

"If they (people with autism) have a learning disability or not, all autistic adults should have equal access to support"

DRAFT

Question 4: Do you agree with the strategic direction of this priority area?

4. Purposeful occupational activities

'Autism ceases to be a label when you have a purposeful occupational activity. You are what you do'

Finding the right opportunities to pursue individual interests and employment

Questionnaire
respondent

Feedback Received Summarised

Being able to find and pursue individual interests and employment was regarded as 'critical' to young people's lives, and over 90% of questionnaire respondents agreed this should be a priority for future development in the Borders.

Leaving school and knowing the options you have is important. Being able to pursue your interests as child, young person or an adult, in a meaningful way, either through further education/training or employment, is also vital.

People have told us that they sometimes do not know the options they have upon leaving school and this can be a source of stress and anxiety for both the individual with autism and their families.

There are barriers which can prevent people with autism from accessing [further education, training and occupational opportunities](#) that were reported through our engagement. Feedback showed that a lack of understanding of autism from employers is thought to be the most significant barrier to obtaining and maintaining employment.

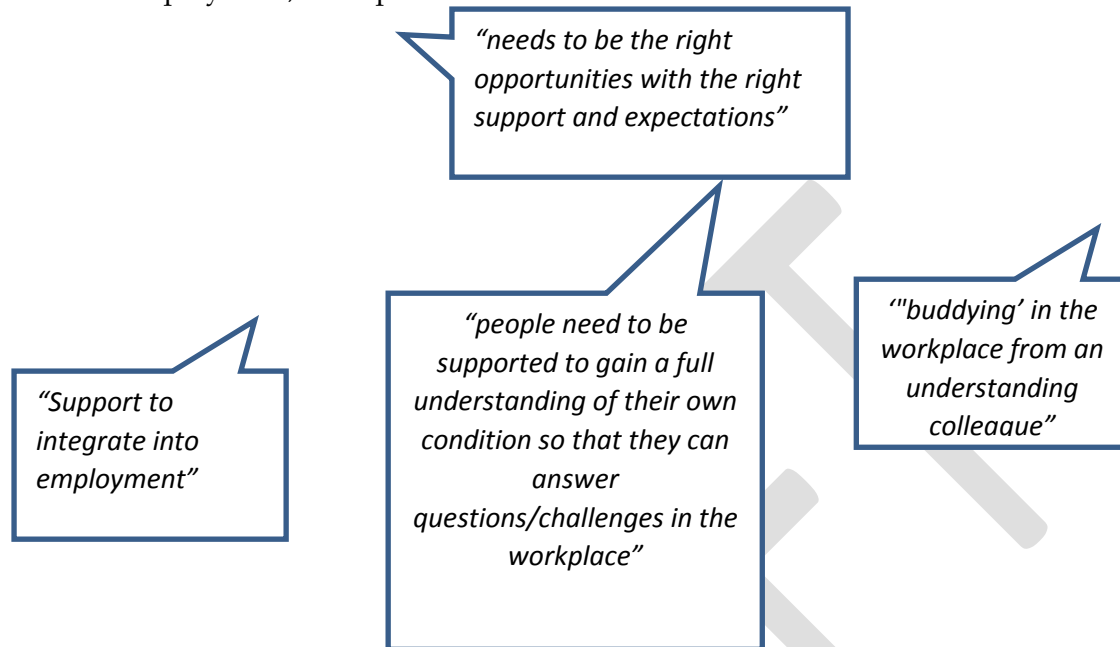
"there should not be barriers to fulfilling one's potential, whatever that may be"

Voluntary work was cited frequently as a good step towards gaining paid employment and a way to actively engage in a personal interest.

It was recognised that in order to be successful in training or further education, some people require additional support, to help manage anxiety and social issues that may arise during the course or work placement. Getting the right support from employment staff who are knowledgeable about autism, to help find and apply for training and jobs, was also raised as

a priority. Autism specific courses were also raised as a method of ensuring access to training was made easier.

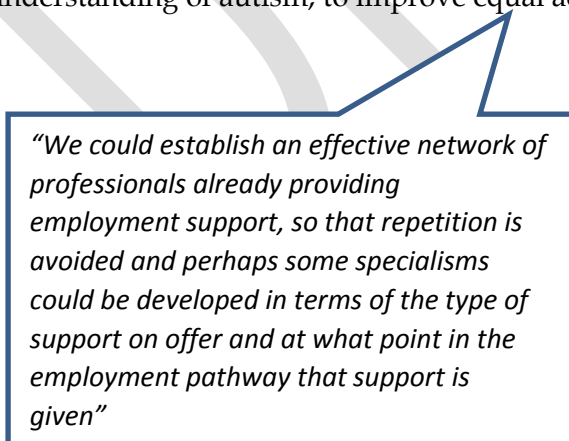
It was also reported that people with autism would benefit from having support available while in employment, to help maintain their role.



Where we want to be

Having a purposeful occupation can provide people with a sense of meaning, enjoyment and social opportunities. In a broader sense, purposeful occupation provides society with economic contributors and this can be valuable to the local community.

We want life-long planning, beginning in education, for people to map out options based on their personal strengths, skills and interests. We also want local employers to develop a better understanding of autism, to improve equal access to opportunities for employment.



Question 5: Do you agree with the strategic direction of this priority area?

5. Social support and opportunities

“Great idea. Of course I crave social activities, like most folk, but do find it difficult, often entering into conflict, I am often unaware of why these conflicts develop, and I seem to have an amazing ability to upset certain people without understanding how”

Opportunities to develop social skills and accessing a range of social opportunities

Questionnaire
respondent

Feedback Received Summarised

Developing more social opportunities and support in the Borders is a priority for the future, with over 90% of questionnaire respondents in agreement.

Social interaction can be a very challenging and stressful experience for people with autism; however this does not mean that all people with autism do not want to mix with other people. The feedback demonstrated that having the choice to socialise was important, and that ‘neuro-typical’ values should not be imposed on this client group.

For some people with autism, having a range of social opportunities is important; ranging from developing community based activities which are tailored to the individual, to more supported means of socialisation. Some people advocated the development of autism specific social services, as a way of interacting with people with the same condition.

“Having a range of options and choices is important. Focus on service user involvement, supported as necessary.”

“The social side can be the hardest bit for those with autism. It is important to find social places that they feel comfortable and to have support workers to help make sure they are in the community more to help with social situations”

It was also thought that the public have a responsibility to become more accepting and understanding of autism, through awareness raising, so that existing community based activities become more accessible for people with autism.

“the general public need to adapt to the needs of others, particularly people with autism, rather than force those with autism to develop social skills with which they have less of a connection (to the neuro-typical psychology)”

There is evidence to show that many people with autism feel that with appropriate social support, quality of life would drastically improve and mental health issues would reduce. Some people said having the opportunity to share their favourite activity with others would help manage their anxiety and provide them with a chance to meet other people.

The feedback shows that some people with autism need specialist *social support*, available locally, *to learn aspects of socialisation* that would allow them to access a greater variety of existing opportunities, for children, teenagers and adults. Transitioning from social activities in children's services to over-16 opportunities was also thought to be key.

Peer mentoring and 'buddying' or befriending schemes received very positive feedback; the one to one nature of the scheme was recognised as essential in working towards broader inclusion and building confidence.

"working one to one and building a relationship with the person, and taking them to social events"

Where we want to be

We want people with autism to have access to a range of social opportunities, which are genuine, varied, and tailored to meet the need and expectation of the individual. The feedback showed that in order to do this, partner agencies need to work together, to make transitioning between services better and to overcome potential funding problems people expressed.

We want people with autism to have more opportunities to learn social skills, in a supported environment, should this suit the individual.

We also recognise that social opportunities need to be available locally; as the geography of the Borders can present numerous challenges to travel, resulting in isolation.

We also want to address the existing barriers to wider community based activities that people with autism want to access.

Question 6: Do you agree with the strategic direction of this priority area?

6. Improving access and provision of housing

“the light at the end of the tunnel is knowing that the person you care for is in appropriate housing for their needs”

Addressing the barriers to finding, securing and maintaining individual housing needs

Questionnaire respondent

Feedback Received Summarised

Moving out of the family home and having a flat or house of your own is seen as a fundamental step towards living independently. For people with autism, this can be challenging, for a number of reasons. Our questionnaire shows that over 90% of respondents agree that improving access and developing the provision of housing in the Borders should be a priority for future development.

Some people told us that they felt there is a lack of appropriate housing options for people with autism in the Borders, which meant that individuals were staying at home with their parents for a longer period of time than is desired.

“My son lives at home, as far as I am aware he has no other alternative”

Some people expressed a need for increased housing stock, available locally, built with the needs of people with autism in mind at the point of planning.

The feedback also reflected that a range of housing options are required, to meet the various levels of need associated with autism. Some people referred to the existing supported accommodation as working well, however others reported a need for more specialist provision to be made available. On the other hand, feedback also highlighted a need for more independent living opportunities, with support to apply for and manage tenancies.

“needs to be autism specific with supervision by confident and well trained staff”

“supported independent housing and a supported application process”

The process for applying for social housing was raised by a significant number of people through our engagement. People felt that the needs associated with autism were not always taken into account when finding or applying for housing. It was thought that the vulnerability of some people with autism should be acknowledged in this process, which should influence the potential areas selected for living.

“the online bidding process in the Borders is not always ideal. It is often hard to tell what the neighbourhood is like and if the house is really suitable for their needs”

Where we want to be

We want people with autism to have equal access to a range of housing options, which are carefully selected, to meet the unique needs of the individual. We want people to know where to access information about housing and who to contact for advice.

We also want to work with our partners, to look to the future, in developing more appropriate housing which has been planned with autism in mind.

Question 7: Do you agree with the strategic direction of this priority area?

7. Ensuring inclusion for people with autism and their families

People will have their voices heard and acknowledged by professionals

'I think it is a great idea. The people who require, and will be using the services are the best people to be involved with these decisions. They are the only ones who can give personal opinions, feedback and advice on current and future services.'

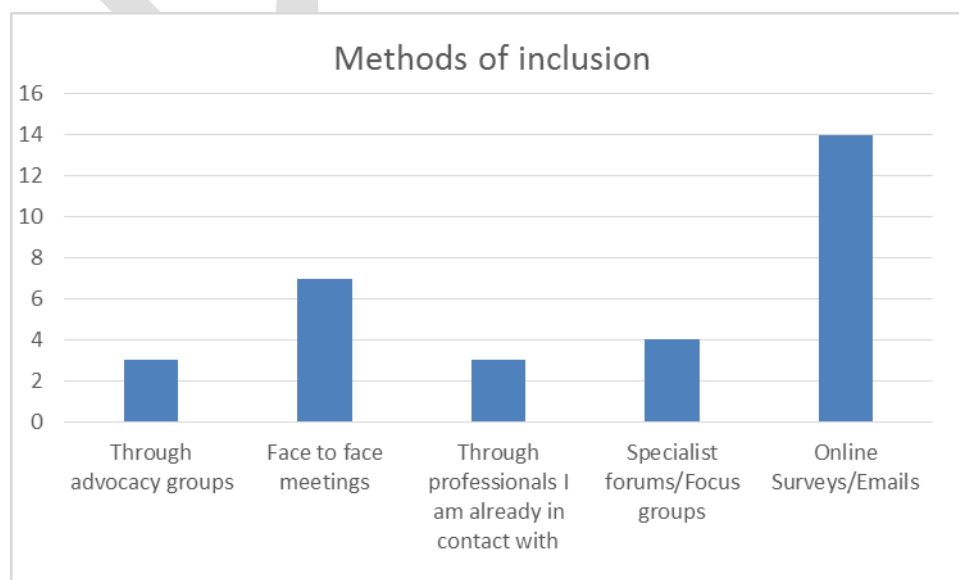
It is essential that the views of people with autism and their families are heard and acted upon. Over 95% of respondents to our questionnaire agree that further developing inclusion or involvement should be an area of development in the Borders, as part of our autism strategy.

People highlighted good practice that exists in education, through the Education Act Scotland, which ensures equality and inclusion. The 'Meeting Around the Child' meetings and the Children's panel are reported examples of this good practice.

The feedback clearly shows that people want to be heard; people told us that listening to parents, carers and people with autism is key to developing tailored services and meeting the needs of the individual. Another key point reported is the need to transfer information collected from stakeholders into action, to make real changes.

"Very important to hear from those who have autism. It is them at the end of the day that live with this (autism)"

People suggested a range of methods for how they could best express their views and opinions. The graph below shows the methods suggested and the number of people that



suggested the method.

From the data, it is clear that online methods are considered a popular, accessible way of sharing opinions and views.

The feedback also stated that effort should be made to find the most suitable method of communication, which might include using writing or pictorial based communication methods, for the individual.

“There is no ‘best’ way (to communicate) as people on the spectrum don’t all respond in the same way – needs an individualised, person centred plan”

Where we want to be

We want people with autism, and their parents and carers, to have equal opportunities to express their opinions and views to knowledgeable professionals, to help manage and plan existing and future services.

We want a range of communication methods to be available, to empower people with autism to have choice, and ensure their voices are heard and taken into account in the future.

Question 8: Do you agree with the strategic direction of this priority area?

Appendix A

List of previous initiatives

Public Health Institute of Scotland Autistic Spectrum Disorders Needs Assessment Report, 2001

<http://www.scotland.gov.uk/Topics/Health/care/adult-care-and-support/learning-disability/Resources/PHIS>

SIGN publication No 98) Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders

<http://www.sign.ac.uk/guidelines/fulltext/98/index.html>

Commissioners of health and social care services for people on the autism spectrum, Policy and Practice Guidance, (2008)

<http://scotland.gov.uk/Publications/2008/03/27085247/0>

Education for pupils with autism spectrum disorders, 2006, HMIE

<http://www.hmie.gov.uk/documents/publication/epasd.html>

National Guidance on the Implementation of Local Area Coordination, Scottish Government, (2008).

<http://www.scotland.gov.uk/Publications/2008/03/27092411/0>

A Guide to Getting it right for every child (GIRFEC) (2008)

<http://www.scotland.gov.uk/Topics/People/Young-People/gettingitright>

Appendix B

Breakdown of current estimated spend on people with autism:

It has been extremely difficult to calculate the current spend on support and services for people with autism. All figures below are indicative only and apply to the current financial year only and may not necessarily be representative.

Joint Learning Disability Service:

The Joint Learning Disability Service calculates that current spend per annum on people with a learning disability and also autism is **£3,202,503**. This comprises of individual packages of care for **59 clients** which equates to an average cost of **£52,690 per person**. The types of support provided within this sum are community support, housing support, personal care, day care, residential as well as other services.

Access to Number 6 One Stop Shop,:

The cost is currently **£15,000** per annum to provide access to people with Asperger Syndrome and High Functioning Autism from the Borders.

Staffing Costs:

It has proved difficult to calculate costs relating to staffing time devoted to working with people with autism. An indicative or proxy figure of **£24,000** per annum has been given as the estimated costs of time devoted by three NHS posts involved in diagnosis and assessment.

It is impossible to calculate what the indicative costs will be, linked to all the time spent by a wide range of NHS and SBC staff in their working with people with autism.'