

**National Autism Services Mapping Project**

# **Scottish Borders Service Map**

**September 2013**

# National Autism Services Mapping Project

## Scottish Borders Council Service Map

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<sup>1</sup> Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people and the world around them. It is a spectrum condition, which means that, while all people with autism share certain areas of difficulty, their condition will affect them in different ways. Aspergers syndrome is a form of autism

<sup>2</sup> Definition of a carer

Throughout this document we use the term "carer" to describe individuals who provides unpaid support to a relative family or friends who has autism. The majority of individuals are parent carers but the term carer also describes other family members such as siblings, grandparents or friends who provide substantial unpaid care.

We use the term support worker to describe individuals providing paid support to individuals with autism

## **1 Background to the National Mapping Project**

The National Mapping Project has been a short term fact finding exercise and analysis of information relating to the delivery of services for individuals with autism in your area. It is designed to map out existing service provision across Scotland in order to build up a full picture of the national position which will help inform future local decisions on autism co-ordination on who will do what and where, and influence national decisions on the investment of Scottish Government funding for autism in the future.

The Service Map presented below is a snapshot of the situation in your area with regard to the delivery of services for people with autism. It is predicated on the information collected from the desk research into policies and practice, people we spoke to at the focus groups and the questionnaires completed by individuals in your area. In some areas there was not a full representation of all stakeholders. The corollary of which is that those who did respond will clearly have had an impact on the picture we have drawn.

The Service Map is not the complete story of the services you deliver in your area, those responsible for the delivery infrastructure already in place and service users will both have additional information not recorded here due to the short term nature of the work and reflective of the level of engagement with the Project.

However, together with the national findings and knowledge of your current delivery, it is hoped this service map will help inform the design and delivery of your Autism Action Plans as agreed under Autism Strategy funding to local authorities.

## 2 Methodology

The Mapping Project gathered information in three ways:

- Desktop research in relation to Data and Strategic Policy
- Online questionnaires for:
  - ➔ People living with Autism
  - ➔ Carers
  - ➔ Statutory providers
  - ➔ Service providers
- Workshops with:
  - ➔ People living with Autism
  - ➔ Parents and carers
  - ➔ Multi-agency groups

The Aims of the Workshops were to identify:

People living with autism:

- I. To gather experience of people with autism about the places, people and activities that help them have a “meaningful life”
- II. Gather information about how the core services contribute to having a meaningful life
- III. Gather ideas of what might happen to improve things and what difference that would make

Carers and parents:

- I. To have a better understanding of what carers want to see in their local areas
- II. To have a better understanding of the local areas and what is making a difference for people living with autism and their families
- III. To identify what would make a difference for them

Multi-agency groups:

- I. To use the 10 indicators for developing best practice as a baseline for discussion
- II. To gather information about how services work in partnership together
- III. To explore the depth of partnership working
- IV. To provide knowledge about the impact for people with autism, through identifying the challenges and gaps in services

### 3 How the service map is organised

From the information gathered throughout this exercise Mapping Coordinators identified a number of recurring themes. It also became apparent that the themes could be arranged under aspects of delivery that individuals talked about. These were: People, Processes, Services, Specialist Services and those issues which were specific to Parents and Carers.

People	Processes	Services	Specific Services	Parents and Carers
Autism Knowledge and Awareness	Carers/Family Support including groups/listening to carers/carers assessment/named person	Advocacy	Autism Specific Services for Children and Adults	Parents/Carers as equal partners
Community and Social Opportunities	Communication and Signposting	Criminal Justice including Police/Autism Alert Card		Carers/Family Support
Environment including sensory	Diagnosis - All aspects	Education/Further Educations – including pre-school/mainstream and autism specific		
Inclusion/Acceptance of autism	Information/Data Sharing	Employment/Employ ability		
People/Professionals who understand	Intervention (universal for all services)	Housing		
Reasonable adjustments to accommodate autism	Multi-Agency/Partnership/Pathway, Communication and Co-ordination of services	Respite		
Transport and Rural Issue	Prevention (early intervention) approach	Services - Access/Gaps/performance		
	Autism Planning Structures	Service Responsibility including lack of service for people with Asperger's and high functioning autism		
	Quality of life/Wellbeing/Feeling	Transitions - all major life transitions		
	Training – all aspects For professionals – a framework for training			

For coherence with the Scottish Strategy for Autism the themes have been for the most part organised within the service map according to the [Ten Indicators](#) for best practice in the provision of effective services as laid out in the Scottish Strategy for Autism.

A particular focus has been offered on issues specific to Parent and Carers and to Quality of Life outcomes for individuals with autism.

A particular focus has been offered on issues specific to Parent and Carers.

## 4 Background for your area

The prevalence estimates in the Public Health Institute of Scotland (PHIS) ASD Needs Assessment Report<sup>3</sup> suggested 60 in every 10,000 people have autism. However, the Scottish Strategy for Autism (Scottish Government, Nov 2011<sup>4</sup>) reports that more recent studies estimate that the prevalence of autism in children and adults in Scotland is around 1 in 100.

The Scottish Strategy for Autism reports the estimated figures by local authority areas (2005). In the Scottish Borders in 2005 the population was 110,240. The estimated autism prevalence of 90/10,000 suggests that approx 992 individuals have autism in the Scottish Borders.

According to Scotland's 2011 Census the population of the Scottish Borders is 113,870. Using the estimated prevalence of 90 per 10,000 detailed in the Scottish Strategy for Autism (Scottish Government, 2011) there would be an estimated 1025 people with autism in the Scottish Borders.

The Scottish Consortium for Learning Disabilities (SCLD, eSay 2011<sup>5</sup>) reports that there are 2992 adults in Scotland with autism who are known to local authorities, most of these adults have a learning disability (LD). SCLD reports that in the Scottish Borders there are 101 adults with an autism diagnosis.

The Additional Support for Learning and Young Carers Report to Parliament (2013<sup>6</sup>) reports that in the Scottish Borders there are 1,757 (recorded) children and young people in education who have additional support needs. The report highlights that 76 (recorded) children and young people in education have autism in the Scottish Borders.

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<sup>3</sup> <http://www.scottishautism.org/autism-knowledge-services/autism%20-%20policy/needs-assessment-report-2001/>

<sup>4</sup> <http://www.scotland.gov.uk/Publications/2011/11/01120340/0>

<sup>5</sup> [http://www.sclld.org.uk/sites/default/files/booklet\\_1\\_-\\_learning\\_disability\\_and\\_asd\\_2.pdf](http://www.sclld.org.uk/sites/default/files/booklet_1_-_learning_disability_and_asd_2.pdf)

<sup>6</sup> <http://www.scotland.gov.uk/Publications/2013/02/7808/0>

In 2005 the Adult Autism Spectrum Disorder (ASD) Co-ordinator post was funded (£54K) from November 2005-November 2006 by the Scottish Government. The remit of the Co-ordinator was to be a 'change agent' in the lives of adults with autism, their families, friends, carers and the services that support them in the Scottish Borders. It was to provide a planning role for NHS Borders and Scottish Borders Council services for adults with autism and their families.

Kirsten Haughey was appointed as the Autism Coordinator for the Scottish Borders. In 2006 she wrote a final report from her funded role as the Coordinator. This document provides guide to services at the time and outlines the duties Kirsten completed.

In March 2013 funding of £35,000 from the Scottish Government for the implementation of the National Strategy has been identified and a Job Description is currently being devised by Bryan Davies from the Scottish Borders Autism Strategy Group to employ a Project Manager to develop the Local Strategy and Action Plan from the National Strategy document, taking into account the Mapping Project data.

There are various policies implemented in the Scottish Borders such as the Early Years Strategy, Short Breaks Strategy or Young Carer's Strategy. Although they do not include any specific autism references, they outline relevant actions under policies detailed.

The school leavers' destination for Renfrewshire in 2010 and 2011 show the following:

Scottish Borders	SLDR Cohort	ASD Cohort	%	Higher Education	Further Education	Training	Employment	Voluntary Work	Unemployed Seeking	Unemployed Not Seeking	Unknown	Positive Destinations	%	ASD Leavers from Specialist Provision	Total ASD Leavers (Publicly Funded Secondary and all Specialist Provision Combined)	Positive Destinations	%	
2011-2012	1,181	7	0.6%	1	4	1	0	0	0	0	0	1	0	6	86%	0	7	6
2010-2011	1,266	9	0.7%	2	5					2				7	78%		9	7

## 5 What we asked and who responded to us

A desktop research exercise was carried out into strategies and policy relating to autism in the Scottish Borders. Seventeen people took part in the multiagency workshop including professionals from health, education, housing and service providers.

In the multiagency workshop people were asked to:

- score how their service is currently doing in relation to the ten indicators of best practice as detailed in the Scottish Strategy for Autism
- discuss a number of case studies detailing what the response to the case study would be in the Scottish Borders
- indicate the breadth and depth of partnership working
- summarise what is working well and what may require further development in the Scottish Borders

Two focus groups were carried with carers involving 17 carers in total. Only 2 carers were caring for adults older than 19 years old.

In the carer workshop people were asked to:

- score and comment on their experience of service provision relating to 7 core services: care and support, health, education, transitions, employment, housing and criminal justice services
- as a group, carers were asked what is working well and possible areas for improvement in the Scottish Borders

Two focus groups were carried out with people with autism involving 7 people. At the time of conducting the focus group the respondents with autism were 14-17 years old.

Online questionnaires for statutory agencies, service providers, carers and individuals with autism were distributed through the Local Authority and service provider networks in the Scottish Borders. There were 3 responses from statutory agencies. Eight responses from service providers: 2 of which from services for children, 1 from services for adults and 5 from services for both children and adults. Eight carers responded: 5 carer respondents were caring for children and 3 carer respondents were caring for adults. Three individuals with autism responded to the online questionnaire.



Focus Groups	Nos	Questionnaire responses	Nos
Multi agency	17	Multi agency	3
Service providers	-	Service providers	8
Parent/Carers	17	Parent/Carers	8
People with autism	7	People with autism	3

## 6 What people with Autism told us

**Key to codes:** the following codes indicate, throughout the document, the source of the data i.e if the information has been gathered from the questionnaires or the workshops and from which group.

Please note that where small numbers responded in any area and there was a possibility of identifying an individual, that information has not been directly quoted and has instead been used to ascertain a trend along with other quotes, information or data.

- M for multi agency workshop
- C for Carers workshop
- I for individuals with autism who took part in a workshop or completed workshop tasks individually
- SAQ for Statutory Agencies Questionnaire
- SPQ for Service Providers Questionnaire
- CQ for Carers questionnaire
- IQ for Individuals questionnaire
- QQ for quantitative data across national responses to questionnaires
- Quotes from individuals are in quotation marks
- DR desk research

	What's working well?	What's not working well?
Quality of Life Outcomes	No comments	No comments
Community and social opportunities	There is a range of opportunities for social interaction offered: social interaction in employment, respite, befriending services through SW, buddy schemes, monthly drop-in meetings, personal social support, personal	The remoteness of some locations often makes it increasingly difficult to access any opportunities for social interaction (IQ).  The presence of other people/strangers can be off-

	<p>diary planning, support to access FE or social gatherings, signposting to other services (SPQ).</p> <p>Being able to take part in social activities such as sports, shopping trips, going on holidays or pursuing interests and hobbies improves overall wellbeing of adults with autism (I).</p> <p>Autism Initiatives in Galashiels provide a range of activities and outreach. General feeling is that it is good to have a hub – where people can get signposted/access outreach services (M).</p>	<p>putting for some people with autism (IQ).</p> <p>Gap between education and sport – there was some consensus amongst respondents that some pupils might not be getting adequate exercise and that provision was patchy across the Borders. There were also some issues raised around provision of appropriate exercise ('not everyone wants rugby!!') for pupils with autism, as their needs might not be met in mainstream education. Specialist units are more likely to provide the right kind of exercise to meet their needs (M).</p>
<p>Inclusion/ Acceptance of autism</p>		<p>4 out of 8 respondents said that the person they cared for did not feel included in the community</p> <p>Main worries of the Carers were the vulnerability of their children making them prone to bullying or being taken advantage of (CQ).</p>

#### Areas for improvement – what needs to change?

- There is a need for being able to use services, which are peer-led and do not require the service users' contacts to be stored on a database (e.g. HUG) (IQ).
- There is a need for social groups for both children and adults with autism – question arises as to how it can be achieved in such a large geographical area and as to how people with similar interests in the different areas can be reached. A possibility of some sort of a mobile service was suggested – a bus was mentioned as a good idea.
- There is a need for creating more inclusive youth groups, organised clubs with appropriately trained staff and support for people with autism to access services or clubs/groups without the presence of their families (CQ).

## 7 What Parents and Carers told us

Parent and Carers were asked to score services between poor (1) and excellent (4). The table below indicates the average scores given. Please, note that there was an additional option to choose – I don't know (5) which have been recorded separately.

Parents and Carers scores for: 'How my area is doing'	
Care and Support response	1.3 Don't know 3
Health response	2.3 Don't know 0
Education and Further Education	3.3 Don't know 2
Transitions	2 Don't know 3
Employment	1 Don't know 5
Housing and Community Support	3 Don't know 5
Criminal Justice Services	No response

Specific issues relating to Parents/Carers		
	What's working well?	What's not working well?
Parents/Carers as equal partners	17 Carers participated (14 dual Carers and 3 single Carers) in 2 workshops. Family, friends, siblings, neighbours, partners, teachers, respite and other professionals were mentioned as the main sources of support	6 out of 8 Carers stated they had no support, 1 added that they could access it if needed (CQ).  Only 2 parents out of 8 stated that the needs of the person they cared for were fully met and added that it was difficult to

	<p>because they provided independence, security, structure, trust, support, awareness of needs and understanding, patience, familiarity, comfort and peace of mind (C).</p> <p>Amongst helpful places home, school, cinema, swimming pool and other leisure activities/services were mentioned because they provided sense of independence, opportunities for social activities, respite for people with autism and parents and acceptance of the community for parents (C).</p>	<p>obtain support from social work or housing services (CQ).</p> <p>Only 1 person was aware of the strategy and 9 out of 17 stated they were not aware (C).</p> <p>Services were generally rated as poor apart from FE/HE services in a couple of instances, which were given a rating of 3 or 4 (C).</p> <p>With regard to independent living, after diagnosis there is a lack of assessment (i.e. how the condition will actually affect the person). Attitude of NHS professionals can sometimes be unhelpful. Adjustments and considerations of NHS staff would be of considerable help (C).</p>
<p>Carers/Family Support including groups/listening to Carers/Carers assessment/named person</p>	<p>Services: Spectrum Support, Borders Additional Needs Group, Riding for the disabled, Stable Life, Music and Art therapy, Educational Psychology, SALT, Social work and school, Andrew Lang Unit, Further Education (Borders College), Dentist Service (special needs dentist – Galashiels – Yvonne Miller), Galashiels Academy (guidance). Transition planning and facilitation is effective in transitions from primary to secondary. Voluntary sector is good, however, difficult to be referred to (C).</p>	<p>There are not enough social opportunities (at appropriate times). There is a gradual approach in services and choice of respite is limited (no options). There is a need for more integrated working and partnership working between services -SW/HC/ED children (C).</p> <p>Some Carers thought that there is a lack of information for parents about what services are out there, there was no help with filling in claims for benefits and content of assessment forms is often inappropriate.</p> <p>Other carers reported that there is not enough communication</p>

		<p>with school or sharing of information. And there is little or no help available to guide through pre and post diagnosis and there is no secondary provision.</p> <p>Other difficulties mentioned:          lack of services for adults;          difficult access to diagnosis;          housing – no options for people to move out so they stay with parents longer; there should be more OT services, which should be part of a holistic approach to support (C).</p>
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Groups were asked to identify three top action points. These varied across groups but have been put in order of priority:

Top three action identified by Parents/Carers in (LA)
1. Diagnosis, assessment, planning and delivery of services/interventions as well as early and post-diagnosis support
2. Standardised ASD training for professionals, training framework, transparent communication, more awareness of ASD and professional attitudes
3. Disability employment, supported living and transition services as well as opportunities to learn life skills and guidance and inclusion of parents in the process of accessing services

### Areas for improvement – what needs to change?

There is a need for more local groups and support for the families; coordination of various support services; early diagnosis; clear and accessible information on available services; more support for siblings and day outings for children with autism; more supported employment opportunities or activities; more accessible clubs and community activities; more respite care; childcare for children above primary school and more appropriate educational provision. It was also noted that diagnosis obtained elsewhere in the UK should be still valid (CQ).

Priorities: diagnosis, assessment, planning and delivery of services, early diagnosis and post diagnosis support; standardised autism training for professionals or framework of training; general autism awareness/educating people; supported living and opportunity to learn life skills; professional attitude/communication (must be honest and transparent & facing gaps face on); availability of disability employment service; understanding and awareness of one's vulnerability; smoother transitions; availability of specialist secondary units like SPECTRUM; guidance through processes (pre/post/accessing services); parent/carer involvement in services and consultation (C).

There was also a wide spread agreement on a lack of services for adults with autism. Respondents were worried about their son/daughter's destination after leaving school. Moreover, there was a group agreement on the stress arising from uncertainty regarding funding (C).

## 8 Statutory and Voluntary Services perspective

Agencies attending Focus Groups	Nos
Health	8
Social Work	1
Education	4
Further Education	1
Criminal Justice	0
Police	0
Employment/Employability	1
Housing	1
Service Providers	1
Other	0

At the multi-agency meeting, people were asked to indicate local progress with the Strategy for Autism against the 10 indicators in the provision of effective autism services as outlined in the Scottish Strategy for Autism. 1 indicates 'work has not yet begun', 2 is 'made a start', 3 is 'good progress' and 4 is 'completed'. Below is the mean score from the local multi agency groups.

Good practice indicator	Mean score
A local autism strategy	2.0
Access to training and development	3
A process for ensuring a means of easy access to useful and practical info about autism	2.6
An ASD training plan	2.7
A process for data collection	3.2
A multi agency care pathway	3.0
A framework and process for seeking stakeholder feedback	2.4
Services that can demonstrate that service delivery is multi agency in focus	2.9
Clear multi agency procedures and plans	2.7
A self-evaluation framework	2.7

## 9 A Summary of Findings in relation to the 10 Indicators of Good Practice

The tables below set out the responses from the information gathered from individuals in your area. They are set out under themes or headings which were developed from the national data sets.

Please note:

The following Indicators have been grouped together. The information gathered did not distinguish between the two aspirations:

2. Access to training and development to inform staff and improve the understanding amongst professionals about autism.
4. An ASD Training Plan to improve the knowledge and skills of those who work with people who have autism, to ensure that people with autism are properly supported by trained staff.

Similarly the following Indicators have also been grouped together for the reasons outlined above:

7. A framework and process for seeking stakeholder feedback to inform service improvement and encourage engagement.
10. A self-evaluation framework to ensure best practice implementation and monitoring.



1.

**A local Autism Strategy developed in co-operation with people across the autism spectrum, Carers and professionals, ensuring that the needs of people with autism and Carers are reflected and incorporated within local policies and plans.**

	What's working well?	What's not working well?
ASD Planning structures	<p>There is a Scottish Borders Autism Strategy Group whose membership should include representation from health, education, social work and the voluntary sector, with additional members co-opted as required. (M)</p> <p>All professionals stated they sought feedback from their clients (e.g. consultation and liaison with parents) (SAQ).</p> <p>Various strategies of involving service users/parents were mentioned: parents invited to planning meetings along with other agencies, fundraising, open meetings, networking events, social networking sites, email, phone, family forums, keyworker and house/project meetings, reviews, service user representative network, including service users as members of the board of management (SPQ).</p>	<p>Some participants were not aware of the process of developing a local autism strategy, but others mentioned they were involved in the process and added that the strategy group has met three times so far and will start on creating a local strategy once the mapping exercise is complete (M).</p> <p>4 providers out of 8 didn't know about the strategy, 3 knew, 1 answered: don't know; only 1 was involved in its development (SPQ).</p> <p>3 respondents stated they didn't know about the autism strategy; 2 people mentioned that there was a clear point of contact, 1 person said the opposite (SAQ).</p>

### Areas for improvement – what needs to change?

Amongst the respondents/organisations/services with scores of 5 (answer: don't know or N/A) in the indicators scoring sheet exercise, Borders Colleges appeared most often (gave a score of 5 for indicators 1, 3-8 and 10) (M). This would suggest that an area for consideration would include how planning is taken forward to be inclusive of all stakeholders.

2.

**Access to training and development to inform staff and improve the understanding amongst professionals about autism.**

4.

**An ASD Training Plan to improve the knowledge and skills of those who work with people who have autism, to ensure that people with autism are properly supported by trained staff.**

	What's working well?	What's not working well?
Training –all aspects. For professionals – a framework for training	<p>Indicator 2 – Spectrum support outreach teachers scored this a 3 – good quality training is offered for teachers CPD, as they are offered training in social education and peer awareness training around transitions. Training is there but it is not always taken up. There was some discussion around whether training could be mandatory (M).</p> <p>1 respondent stated that they had not begun to work on Indicator 2 concerning access to training and development, 5 said they had made a start, 6 said they</p>	<p>3 out of 8 service providers said there were further autism-related training needs in their organisations: training is offered via CPD directory, but it is not mandatory. (SPQ)</p> <p>Training offered to staff often depends on workload capacity and study leave budgets; there is limited uptake, especially in the health sector/adult services (M).</p> <p>There was little awareness of a training plan for all services; training seems to be fragmented and dependent on various factors (e.g. resources). Accreditation, level of</p>

	<p>had made a good progress, 2 have completed the work (M).</p> <p>5 respondents stated that they had not begun to work on Indicator 4 regarding an autism training plan, 2 had made a start, 4 had a good progress, 1 had completed the work, and 2 didn't know the answer to this question (M).</p>	<p>provided training and unwillingness of staff to take up training were also raised as the main issues (M).</p>
<p>People/professionals who understand</p>	<p>Places which help: SALT services, staff at Howdenburn House, Grove School (Berwick), spectrum outreach support service, Andrew Lang unit and college. Support from family and friends were also mentioned as very important to adults with autism (I).</p>	<p>Some respondents with autism described visits to hospital as unpleasant though others stated that they liked going to doctor or dentist appointments as they kept them healthy (I).</p>

#### Areas for improvement – what needs to change?

- There is a need for more/continuing training on autism awareness; many staff are unaware of the impact autism has on certain aspects of the curriculum (SAQ).
- Having training across all agencies and opportunities to develop more detailed knowledge (MA level) would be helpful. Training on how to support families and see life from their perspective would be useful too (SPQ).
- Better training required for those in mainstream services and for public in general (M).
- There is a need for giving people with autism more notice about changeable things (e.g. timetables) and raising social awareness of autism in order to remove prejudice and barriers to inclusion (I).

3.

**A process for ensuring a means of easy access to useful and practical information about autism, and local action, for stakeholders to improve communication.**

	What's working well?	What's not working well?
Autism knowledge and awareness	6 out of 8 service providers said they had a responsibility in raising public awareness. This was achieved by organising workshops to mainstream staff and other agencies as well as through leaflets, email and phone conversations, modelling good practice, inclusive support approaches, positive behavioural approaches, appointing dedicated members of staff with autism remit and involving other professionals in service training (SPQ).	The respondents involved said their organisations did not have any role in raising awareness of autism (SAQ).
Communication & signposting	<p>Helpful elements: guidance from family members, assessment by SALT, PECS, liaison with parents, person-centred plans used as strategies to support communication with clients with autism (SPQ).</p> <p>Various strategies are adopted to ensure easy access to useful and practical information and improve communication, e.g. classroom support following assessment, involvement of voluntary organisations and other agencies, information sheets for parents/carers included in the daily pupil diaries, service user and carer groups attendance, the website</p>	

	(M).	
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Areas for improvement – what needs to change?
<ul style="list-style-type: none"> <li>• 2 out of 3 professionals stated there was a clear point of contact for autism service provision, but these were individual members of staff within their services rather than an autism coordinator for the whole LA (SAQ).</li> <li>• 4 respondents stated that they haven't begun to work on Indicator 3 regarding a process for ensuring a means of easy access to useful and practical information about autism, 4 stated they'd made a start, 3 stated they'd made a good progress, 2 have completed the work, 1 didn't know the answer to this question (M).</li> </ul>

**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.**

	What's working well?	What's not working well?
Information/Data sharing	1 respondent stated that they had not begun to work on Indicator 5 regarding a process of data collection, 5 respondents had made a start, 1 respondent had made good progress, 5 respondents had completed the work and 2 didn't know the answer to that question (M).	<p>There would appear to be no formal recording or prevalence rates for service users with autism- people with autism are included in the following categories: requiring extended learning support, people with disabilities, vulnerable tenants.</p> <p>Existing databases within the NHS often do not record the number of adults with autism or do not provide any</p>

		<p>autism-specific information (M).</p> <p>Some respondents stated they did not have the time within their teams to create a self-evaluation framework through improvements plans. Education Scotland resources and audit by the Autism Alliance Project were used to ensure best practice implementation and monitoring (M).</p> <p>6 out 8 service providers stated that their service did not record how many service users were using SDS (SPQ).</p>
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**Areas for improvement – what needs to change?**

**6.**

**A multi agency care pathway for assessment, diagnosis and intervention to improve the support for people with autism and remove barriers.**

	What's working well?	What's not working well?
Diagnosis – all aspects	<p>Indicator 6 – a multi-agency pathway was given a score of 3 for LD services in general but not for autism specific. CAMHS also gave it a score of 3, as there is a good, well-developed pathway for children with autism across assessment diagnosis and intervention (M).</p> <p>9 out of 15 respondents from Multi agencies felt that</p>	<p>Barriers were identified by carers, these included: difficult access (service users forced to obtain their diagnosis in England), lengthy (in one case it took 16 years) and complex process, misdiagnosis, not enough information during the process or support after, lack of communication between professionals and parents (CQ).</p>

	<p>good progress was being made with the development of a multi-agency plan 9M).</p> <p>General picture across the Borders – good multi agency care pathway for adults with LD but not autism specific. There is a big gap for those who have autism but have no LD (M).</p> <p>Some respondents stated they had developed a diagnostic pathway, but it was not a multi-agency one (LD service). Others added they were working towards it or were a referral agency (e.g. colleges) - additional post diagnostic interventions were assigned on an individual basis. According to the NHS Borders there is a rudimentary guidance available for adults and relatives to regional autism service (M).</p>	
<p>Interventions (universal) for all services</p>	<p>2 out of 3 professionals said they made information about services accessible through an SDS ASN handbook, contacts with and visits to secondary schools (SAQ).</p> <p>Information was made accessible via website, printed materials, leaflets from different services, face to face meetings, publicity, social networking sites, word of mouth, multi-agency team information dissemination (SPQ).</p>	<p>4 out of 8 services providers said there was no clear point of contact for enquiries about autism services. (SPQ).</p>

<p>Multi agency/Partnership/ Pathway, Communication and Co-ordination of services</p>	<p>Educational establishments are involved in the diagnostic process, SALT and OT are also involved in the interventions provided (SPQ).</p> <p>Indicator 8 - Learning Support Services scored a 3 suggesting that service is developing a well coordinated approach (M).</p> <p>Many respondents stated they worked for a multi agency team; where it wasn't the case, others added that they sought information from other agencies in order to meet the needs of learners, but weren't part of a multi agency service delivery (e.g. colleges) (M).</p>	<p>2 out of 3 professionals mentioned reviews and multi-disciplinary diagnostic process for people with autism when asked about a multi agency care pathway, but added that getting all professionals at meetings is very difficult and a barrier to making decisions. (SAQ).</p> <p>Barriers to multi agency working include: insufficient knowledge of other agencies, time and resources limitations, lack of support towards voluntary organisations, lack of coordinated approach or local strategy (SPQ).</p>
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Areas for improvement – what needs to change?
<ul style="list-style-type: none"> <li>• There is a need for more training and raising awareness (for CAMHS and SW services especially), as there is insufficient knowledge and understanding leading to misdiagnosis. Early assessment and intervention as well as post-diagnostic support should be provided much sooner and more efficiently. More communication with parents and person-centred approach to assessment are needed (CQ).</li> <li>• There is a good multi agency care pathway for adults with LD but it is not autism specific and there is a big gap for those who have autism but have no LD (M).</li> <li>• There is a need for targeted autism strategy delivered by a partnership of specific agencies, coordinator offering a directory of services available in the region as well as raising awareness of autism and organising training. There should be some strategic investment across Scotland (SPQ).</li> <li>• 2 respondents stated they had not begun to work on Indicator 6 concerning a multi agency care pathway, 4 had made a start, 3 had</li> </ul>



made a good progress, 2 had completed the work, 3 didn't know the answer (M) These inconsistencies are an area for consideration.

**8.**

**Services that can demonstrate that service delivery is multi agency in focus and coordinated effectively to target meeting the needs of people with autism.**

	What's working well?	What's not working well?
Criminal Justice including Police/ Autism Alert Card	<p>2 Carers out of 8 said that the needs of the person they cared for were accommodated by the criminal justice professionals (CQ).</p> <p>2 out of 3 respondents stated they used an autism alert card (one of them had an ARGH one as it was easy to access and they didn't need to register in order to have it); they used it whenever in contact with the police force (IQ).</p>	<p>Only 2 carers out of 8 answered the question about the autism alert card – due to the age of their child/young adult (CQ).</p>
Education/Further Educations – including pre-school/mainstream and autism specific	<p>Carers recorded many positives including additional training for teachers, support from OT, additional aids (e.g. ear defenders, quiet areas etc.), coordination of services and education, listening to parents and support workers, having an IEP (CQ).</p> <p>Attending mainstream education was perceived as an advantage/achievement; one person experienced</p>	<p>2 parents out of 8 stated they didn't have any support and experienced insufficient and difficult access to educational support (e.g. home visiting teachers, place in a LA day centre, a specialist nursery placement). They stated the same about the move into pre-school education (CQ).</p> <p>3 carers out of 8 stated that their child went to FE/HE, but there was no support or alternative options offered</p>

	bullying at school (IQ).	(CQ).  Nature of ASD often makes it increasingly difficult for an individual to ask for support in adult life whereas parents are not allowed to do it on their behalf and professionals do not liaise with them (CQ).
Employment/ Employability	Only 1 respondent out of 3 worked at the time of the survey being conducted and it gave them a sense of everyday purpose in life; they added they had excellent support from their boss' and from Ways 2 Work Borders (IQ).	2 Carers out of 8 answered the question about employment and they said that their child didn't have a job and wasn't looking for one (CQ).  There was some discussion around ability to work – people judged on whether they can physically work (example of a person who lost DLA because they were deemed fit to work but were in fact unable to because of autism). People with autism need the right (specialist/individualised) support. Employers need to be encouraged to employ people with autism and there was some discussion around the fact that they need some incentives to do that (M).
Housing	All 3 respondents lived independently, either with their partner/children or alone (IQ).	Financial limitations were mentioned as barriers to accessing ideal accommodation in the desired neighbourhood (IQ).
Transport and Rural Issues	Respondents stated that they enjoyed travelling independently to college or chosen places of leisure (I).	Unreliable and insufficiently frequent buses/trains or remoteness of some locations often makes it increasingly difficult to access any opportunities for social interaction (IQ).

<p>Autism Specific Services for Children and Adults</p>	<p>5 out of 8 services are targeted towards individuals with autism: a range of services provided, e.g. vocational support, speech and language assessment, occupational therapy assessment, educational psychology, neurodevelopmental assessment (SPQ).</p> <p>All respondents stated they gathered feedback from their clients on a regular basis. However, it was often a general process not geared towards the needs of people with autism. Respondents also added that developing a framework for gathering feedback from stakeholders was difficult due to lack of autism-specific services in the area (M).</p> <p>Parents mentioned various strategies for involving service users, e.g. parents were invited to planning meetings along with other agencies, fundraising, open meetings, networking events, social networking sites, email, phone, family forums, keyworker and house/project meetings, reviews, service user representative network, service users appointed as members of the board of management (SPQ).</p>	<p>Service providers reported that there was insufficient knowledge of autism specific services in the area and said that a targeted employability agency would be useful. There is a need for more resources to support home/school links and more flexible respite is needed. There is limited access to suitable out of school activities. Diminished resources make it challenging to provide support in mainstream education or during transitions, especially for people with AS/HFA who fall through the support gap.</p> <p>There is a gap in autism specific services in the area - generic services often don't take on board specific needs of service users with autism and there is not enough appreciation or recognition of the voluntary sector (SPQ).</p>
<p>Services - Access/Gaps/performance</p>	<p>A range of services mentioned as helpful/efficient: vocational support, primary class units for pupils with autism, support centres, outreach services, complex needs base in local schools, advocacy, respite, training, consultancy, housing and social support, music therapy,</p>	<p>Difficulties with access to social work services were mentioned - 2 out of 3 respondents (1 of them stated that they would like to have some support, the other stated they did not need it).</p>

	<p>psychiatric support (CQ)</p> <p>1 respondent stated that they received social work support with tenancy and employment, which helped them deal with their father's death and live independently (IQ).</p>	
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#### Areas for improvement – what needs to change?

- Discussion on reliance on a regional service - regional service is a vulnerable service and there is a need for a funded protected service. Without it diagnostic services for adults will not continue. LD services provide support but majority of referrals are for people without a LD. There is a need for a local adult diagnostic service (M).
- Priorities: anti-bullying campaigning in pre-school services (examples of bullying experienced from school staff and other pupils were provided); not enough support available; more support for parents/carers in order to improve their quality of life; more training for professionals; more specialist provision should be made available, especially in mainstream education as it is not accessible enough; more befriending services and after school clubs; more funding for individual support to build relationships and develop social skills; consistency of educational provision and support; more training and raising awareness of autism; more support in the local community and FE/HE-ASN units (CQ).
- There should be realistic understanding of abilities of people with autism and their difficulties with travelling. There is a need for supported workshop with appropriately trained staff. More coordination, support and action is needed (CQ).
- Main hopes and desires of the Carers were for their children to live independently or in a shared supported flat with carefully chosen flatmates. They also wanted their children to take up employment/education, be safe in their local community and develop more social awareness skills (CQ).
- There is a need for more independent living services and better accommodation conditions at home (separate bedroom for a child/adult with autism) (CQ).
- Access to services is more difficult for people with AS/HFA (M).
- There should be more focus on person-centred planning instead of providing generic services on the basis of their lower price (SPQ).

- ‘Young people are supported until they leave school but then they are out on their own unless they have a diagnosis of LD – there is a lack of support re transitions and employment etc’; ‘LD services are working well (multi agency LD team), but the diagnostic service could be more multi agency’; ‘SW and Education will fund packages but need LD; in adult services the biggest gap is for those who don’t have a LD – they need post diagnostic support re housing needs, work, social activities’ (M).
- Main worry of the Carers was the inconsistency in staffing and service provision as well as lack of communication with them and not taking their wishes/opinions on board (CQ).
- The invisible nature of autism often makes it increasingly difficult to access support as service users are not considered to need it in the eyes of some professionals (IQ).

7.

**A framework and process for seeking stakeholder feedback to inform service improvement and encourage engagement.**

10.

**A self-evaluation framework to ensure best practice implementation and monitoring.**

	What’s working well?	What’s not working well?
Advocacy	No comments	<p>5 respondents from the multi agency group stated they had not begun to work on Indicator 7 regarding a framework and process for seeking stakeholder feedback, 4 had made a start, 2 had made good progress, 2 had completed the work and 1 didn't know the answer to this question (M).</p> <p>4 respondents from the multi agency group stated they had not begun to work on Indicator 10 regarding a self-evaluation framework, 4 had made a start, 2 had made</p>

		good progress, 3 had completed the work and 1 didn't know the answer to this question (M).
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Areas for improvement – what needs to change?

9.

**Clear multi agency procedures and plans which are in place to support individuals through major transitions at each important life-stage.**

	What's working well?	What's not working well?
Transitions – all major life transitions	<p>Advocacy services, local referral pathway and attendance at transition meetings mentioned as support strategies (SPQ).</p> <p>Primary to secondary school: visits to various educational establishments mentioned as helpful (CQ).</p> <p>Secondary education: forward planning, slow introduction to the new educational setting involving visits from support staff from the previous establishment mentioned as helpful approaches (CQ).</p> <p>Individualised support in residential school involving support from SALT, OT and physiotherapists mentioned as useful (CQ).</p>	<p>Primary and secondary education: insufficient support provided at the point of transition (3 out of 8 parents stated there was no support available) (CQ).</p> <p>Out 3 respondents, only 1 stated that they knew what options were available to them after leaving school, but this was due to the support of family or friends instead of official establishments/destinations, such as HE or employment; 2 respondents found leaving school easy (IQ).</p>

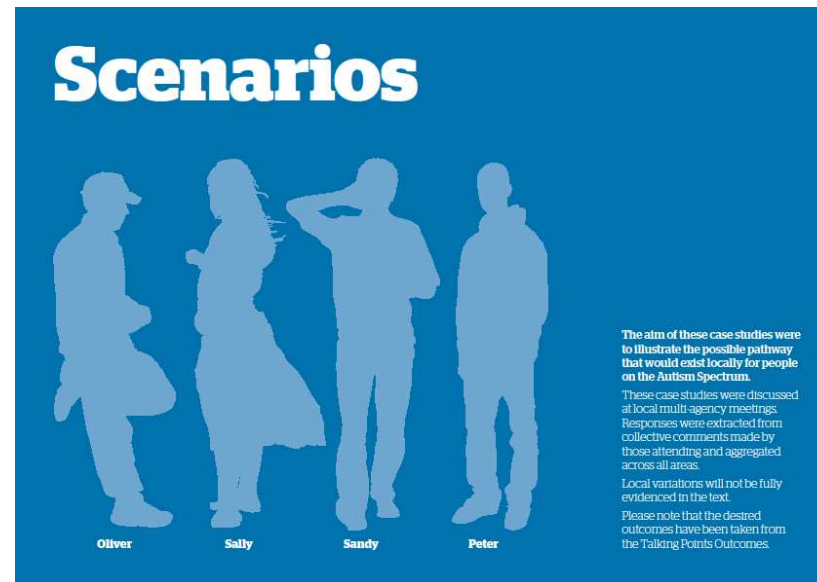
### Areas for improvement – what needs to change?

- Primary to secondary transition: coordinated plans, more support and information on available options and visits to secondary school prior to the transition are needed (CQ).
- Secondary to adult life transitions: more support from social work is needed (CQ).
- There is a need for more autism-specific multi-agency planning in order to handle transitions systematically, especially when one is still in the process of obtaining a diagnosis of autism (M).

## 10 Scenarios

During the course of the project the Mapping Coordinators employed a number of case studies to help agencies determine how they worked together with individuals. Of all the case studies offered four were used more often than others. Below you will find an illustration of one of those case studies with the information extrapolated from across Scotland to give a picture of what is likely to happen. This will be useful in measuring what's happening locally against the information drawn nationally.

To access the results of the case studies double click on the image below and then click on each named case study to review the results. If you are unable to access the PDF through the image please double click on the icon below.





## 11 Moving Forward

The information presented above, as stated in the introduction, offers a snapshot of the situation in your area with regard to the delivery of services for people with Autism and their families. The Service Map is not the complete story of the services you deliver in your area, However, together with the National findings and knowledge of your current delivery, it is hoped this service map will help inform the design and delivery of your Autism Action Plans as agreed under Autism Strategy funding to local authorities.

The information from the entire National Autism Services Mapping Project, across all local authorities in Scotland, will be gathered together and a full report published. The Scottish Strategy for Autism web site has up to date information on the implementation of the strategy for your information <http://www.autismstrategyscotland.org.uk/>