

National Autism Services Mapping Project

Moray Council Service Map

September 2013

National Autism Services Mapping Project

Moray Council Local Service Map

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¹ 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

² 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.

4 Background for your area

The prevalence estimates in the Public Health Institute of Scotland (PHIS³) ASD Needs Assessment Report suggested 60 in every 10,000 people have an autism. However The Scottish Strategy for Autism (Nov 2011)⁴ reports that more recent studies estimate that the prevalence of ASD in children and adults in Scotland is around 1 in 100.

The Scottish Strategy for Autism 2011 highlights the estimated prevalence figures by local authority area (2005 figures.) In the Moray area in 2006 the population was 86750. The estimated autism prevalence was 90/10,000, suggesting that 781 people have autism in Moray.

According to Scotland's **2011** Census the population of Moray is 93,300. Using the estimated prevalence of 90 per 10,000 detailed in the Scottish Strategy for Autism there would be an estimated 839 people with autism in Moray.

The Scottish Consortium for Learning disabilities (SCLD) reports (eSAY '11) that there are 2992 adults in Scotland with an ASD who are known to local authorities, most of these adults have a Learning Disability (LD.) SCLD reports that in Moray there are 94 adults with autism.

The 'Additional Support for Learning and Young Carers Report to Parliament' (2013)⁵ states that in Moray there are 1,731 (recorded) children and young people in education who have additional support needs. The report highlights that in Moray 123 (recorded) children and young people have autism in Education.

Moray has developed an autism strategy in partnership with Health and Social care "A strategy for Adults in Moray with Autism" 2011-2014⁶. The strategy is aimed at adults with autism without an LD who are over 18 years old or are over the age of 16 and have left school education. The strategy does not include those with autism and LD as it is highlighted that these people have access to LD services. It states that there are currently 61 adults with

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

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

⁵ <http://www.scotland.gov.uk/Publications/2013/02/7808>

⁶ <http://www.moray.gov.uk/minutes/data/HC20120808/Item%209-Appendix-ASD%20Strategy.pdf>

autism in Moray that are known to services. However it was reported, with reference to the Scottish Governments estimates, that there may be undiagnosed adults in Moray.

The Moray strategy sets out 5 aims:

Aim1: To increase awareness and understanding of autism for staff.

Aim2: To re-establish a clear, consistent pathway for diagnosis

Aim 3: To improve access for adults with autism to the services and support they require

Aim 4: Support adults with autism into work

Aim 5: Enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities

The Moray Strategy highlights that they have an employment support service which has an employment support worker specifically for adults with autism, detailing that support is provided from transition from school to employment or FE. The strategy states that in the last 3 years 87 people have received support from this service.

Moray have also developed an Autism Partnership board with the aim of bringing together adults with autism, their carers, core services, NHS and service providers in order to assist with the implementation and the aims of the Moray ASD strategy.

Moray has developed a Local Housing Strategy (LHS) 2013-2018 ⁷ which makes specific reference to people with autism and their potential housing needs. The LHS highlights that Moray council will continue to provide an “equitable person centred, needs led approach” to housing in Moray. The LHS also highlights that for the duration of the LHS there will be a commitment to raising awareness of autism amongst housing staff. The LHS strategy references 2 strategic aims that are stated in the Strategy for adults with autism in Moray which are of relevance to housing:

- Increase awareness and understanding of autism for staff
- Improving access for adults with autism to the services and support they need to live independently within the community

The outcomes detailed in the LHS are that:

- There is an adequate supply of appropriate housing for people with autism
- Ensure that housing service providers have a better understanding of autism issues
- In the strategy for autism it states that “we will make it easier for adults with autism to choose how they live and get the help they want and need to do this”

Moray council received funding from the Scottish Government to increase awareness and understanding of autism and to develop citizen leadership. In July 2012 people with autism were recruited to take part in citizen leadership training in order for them to become trainers in Moray, this was termed the citizen leadership project. 4 citizen leaders are

⁷ <http://www.moray.gov.uk/downloads/file84154.pdf>

currently part of an autism training team delivering autism awareness training to services that request it.

The service improvement plan 2012/2013 for adult community care services highlights that specific training on autism will better prepare staff for working with individuals with autism and their families. The document states that training will also assist in improving the standard of work within day services. The service plan objective aims to improve management and care of people with autism.

Recent developments in Moray are that Moray council and NHS Grampian are developing a strategy for Autism in Moray which covers all ages and services (2014-2024) Anne Pendery is the lead for the development of this strategy.

5 What we asked and who responded to us

A desk top research exercise was carried out into strategies and policy relating to autism in Moray. 13 people took part in the multiagency workshop including people from Housing, Police, Community MH team, employment services, education and FE, Social Work, 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 Moray
- Indicate the breadth and depth of partnership working
- Finally summarise what is working well and what may require further development in Moray

One focus group was carried out with carers involving 12 carers. 3 carers were caring for someone with autism aged between 0-9. 6 carers were caring for someone with autism aged between 10-19 and 3 carers were caring for someone with autism aged between 20-29.

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 Moray

Service providers and the Local Authority (LA) were contacted to assist in arranging a focus group to engage with people with autism. At the time of the National Autism Mapping Project Moray LA were also consulting with people with Autism and their Carers regarding what services and resources they would want from a Moray Autism One Stop Shop. Furthermore consultations had been done prior to the development of the Moray ASD strategy. There were concerns from the LA of consultation fatigue and duplication. LA professionals advised that they had asked people with autism to contribute to the National autism mapping project through a focus group or via the questionnaire, the people that were consulted chose the latter.

Online questionnaires for statutory agencies, service providers, carers and individuals with autism were distributed through the LA and service provider networks in Moray. At the Moray Autism partnership board in November 2012 the work of the National Autism Mapping project was also highlighted. In total, 34 people in Moray responded to the online questionnaires. There were 15 respondents from statutory agencies and 3 respondents from service providers. In the carer questionnaire there were 14 respondents; 11 respondents were caring for children and 3 respondents were caring for adults. 2 individuals with autism responded to the questionnaire:

Focus Groups	Nos	Questionnaire responses	Nos
Multi-agency inc Service providers	13	Multi-agency	15
		Service providers	3
Parent/Carers	12	Parent/Carers	14
People with autism		People with autism	2

6 What people with Autism told us

Key to codes: the following codes, throughout the document, indicate 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

	What's working well?	What's not working well?
Quality of Life Outcomes	It was felt that sometimes reasonable adjustments were made in education and that teachers were helpful. Support services were also said to be positive and provide opportunities (IQ)	
Community and social opportunities	Respondents noted that social interaction opportunities were available (SPQ) 100% of respondents said that opportunities for social interaction were included in care plans (SAQ) FE/HE was noted to be a source of social opportunities (IQ) Some respondents said that Elgin High Schools social support was good, however this support is no longer available (C)	<p>13% of respondents said that the person they care for feels included in their local community (CQ)</p> <p>13% of respondents said that the person they care for had friends or relationships in their lives other than family members (CQ)</p> <p>100% of respondents said that the person they care for faced social challenges in primary education (CQ)</p> <p>100% of respondents said that the person they care for faced social challenges in secondary education (CQ)</p>

Issues for consideration
It was felt that the social aspect of education was an area of difficulty for some people with ASD (CQ) as well as community inclusion (CQ)

7 What Parents and Carers told us

The word cloud below represents proportionately, some of the things that carers felt were working well in Moray. The larger the word the more often the word was said. The word cloud does not necessarily represent the group consensus.



Some respondents said that the support received from education was good as a result of an ASN base and school health services. Some positive experiences of the Rock Academy and support from Moray College were highlighted with professionals said to be consistent and supportive. Some positive experiences of transitions and family involvement were noted. It was highlighted that individual professionals made a difference to a person's experience of services i.e. some professionals were reported to be accommodating and understanding. Respondents felt that the Moray ASD strategy was a good start as employment support is recognised in the strategy. However it was highlighted that the strategy does not meet the needs and ages of everyone with autism. Some respondents reported positive housing support from their LA as well as good respite services through the service Moray options.

In the Carer focus group, Carers were asked to score service provision within seven core services between poor and excellent. The table below indicates the scores given. Please note that not all carers responded to all questions and some carers responded twice if they cared for more than 1 person with ASD of differing ages:

Parents and Carers scores for: 'How my area is doing'	
Care and Support response	Poor x5 Satisfactory x1 Good x4 Excellent x0
Health response	Poor x5 Satisfactory x2 Good x6 Excellent x0
Education and Further Education	Poor x5 Satisfactory x1 Good x5 Excellent x2
Transitions	Poor x4 Satisfactory x4 Good x3 Excellent x0
Employment	Poor x2 Satisfactory x1 Good x0 Excellent x0
Housing and Community Support	Poor x1 Satisfactory x1 Good x0 Excellent x3
Criminal Justice Services	Poor x0 Satisfactory x1 Good x0 Excellent x1

Specific issues relating to Parents/Carers		
	What's working well?	What's not working well?
Parents/Carers as equal partners	It was highlighted that there are opportunities for carer engagement in the recently formed ASD adult partnership board where representatives from LA, NHS, Service providers, carers and people with autism meet and are consulted quarterly (M) 90% of respondents said that they sought feedback from service users/carers (SAQ) Some service providers noted that carers are involved in consultation on policy and the design of training (SPQ)	Some respondents from the carers group felt that there needs to be more communication and involvement of the family i.e. during transitions, in education and in health (C) "listening to carers and people with autism, isolation is a killer" (CQ)
Carers/Family Support including groups/listening to carers/carers assessment/named person	No comments	<p>50% of respondents said that as a carer they had some level of support (CQ)</p> <p>43% of respondents from the statutory agency questionnaire said that carers were offered a carers assessment (SAQ)</p> <p>50% of respondents from the carers questionnaire had heard of a carers assessment/support plan (CQ)</p> <p>36% of respondents from the carers questionnaire said that they have a carers assessment/support plan in place (CQ) with some reporting that access to a carers assessment was difficult (CQ)</p>

		Some respondents from the carers group felt that more support for parents and carers is needed i.e. more support groups and inclusive of sibling support (C)
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Groups were asked to identify top action points which are outlined below:

Top action identified by Parents/Carers in (LA)
1. More training, awareness and understanding in all services and society
2. Improve communication and involvement of family i.e. in education, in health and during transitions
3. Improve service provision i.e. more social opportunities, improve local health services and more employment opportunities
4. More housing opportunities “help people progress toward independence and have services that meet this need”

The word cloud below represents proportionately, some of the things that carers felt needed to improve in Moray. The larger the word the more often the word was said.

Issues for consideration



Some respondents from the carers group felt that the environment in hospitals does not always meet the needs of people with autism and that there is a lack of health provision in rural areas. Some respondents felt that the diagnosis process needs to improve with regard to expertise of professionals, the wait for a diagnosis and post diagnosis support. It was also felt that more support is needed in education to ensure the right environment and support for people with ASD as well as an improvement in communication between schools and carers and more family involvement. Respondents also felt that an advocacy service that covers education would be beneficial. Respondents felt that more training and awareness amongst services and professionals is required. Some respondents felt that there needs to be more support, provision and opportunities for people with Asperger’s Syndrome, reporting that their needs are not always recognised due to a lack of understanding of Asperger’s syndrome and that the eligibility criteria is a barrier to services and support opportunities. Opportunities for housing and employment for people with autism were also reported to be required. Transitions were reported to be patchy with some respondents reporting that transitions were good until the move from education to adult services. Some respondents also reported a lack of communication and family involvement during transitions. Respondents were concerned about the lack of future planning and progression toward independence stating that opportunities were limited when people reach adult services.

8 Statutory and Voluntary Services perspective

13 people attended the multi agency workshop as indicated below:

Agencies attending Focus Groups	Nos
Health	0
Social Work	4
Education	1
Further Education	1
Criminal Justice	0
Police	1
Employment/Employability	1
Housing	1
Service Providers	4
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
Access to training and development	3
A process for ensuring a means of easy access to useful and practical info about autism	3
An ASD training plan	2
A process for data collection	2
A multi-agency care pathway	2
A framework and process for seeking stakeholder feedback	2
Services that can demonstrate that service delivery is multi-agency in focus	2
Clear multi-agency procedures and plans	3
A self-evaluation framework	2

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>It was reported that there is “a strategy for Adults in Moray with Autism” which is monitored via an ASD partnership board which has representation from people with autism, carers, Health, LA and service providers (SAQ) Respondents from the multiagency workshop highlighted that the Adult strategy is for those with ASD and no LD over the age of 18 or for those over the age of 16 if the person has left school education (M)</p> <p>It was said that there is an identified lead for ASD in adult services (M) however from the Statutory agencies questionnaire it was identified that not all core services are aware of who this is (SAQ)</p> <p>A respondent from the multiagency group highlighted that the Local Housing Strategy for Moray includes a section on the housing needs for people with autism (M)</p> <p>Voluntary organisation, Cornerstone, have their own autism strategy in consultation with people with autism</p>	<p>Respondents in the carers group were aware of the local strategy and respondents raised issues that the Strategy for Adults in Moray with Autism excludes individuals with autism and LD and excludes children (C) It was highlighted in the statutory agencies questionnaire that there is no autism strategy for children’s services and children’s services respondents were unsure of the progress in this area (SAQ)</p> <p>From both the statutory agency questionnaire and multiagency workshop it was stated that people were unclear of the NHS involvement as equal partners in the adult ASD strategy (2011-2014.) This was said to be as a result of structural changes since the local strategy was published (M, SAQ)</p> <p>There is an autism strategy for adults however it was highlighted in the statutory agency questionnaire that not all core services are aware of this: 47% of respondents were aware of the local autism strategy in their area, 20% of respondents were not aware and 33%</p>

	, however this is not in the public domain (M)	of respondents did not know (SAQ)
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Issues for consideration
<p>It was highlighted that there is no clear lead for autism in children’s services (SAQ)</p> <p>An autism strategy that covers all ages and diagnoses was said to be required to be developed (SAQ, M, C)</p> <p>It was stated by one respondent in the statutory agency questionnaire that an improved structure within the authority framework is required in order to work toward multi-agency working (SAQ)</p> <p>It was also recognised at the multiagency workshop that an audit and evaluation of service provision is required in order to identify if and how the strategy improves services (M)</p> <p>Statutory agencies and service providers stated that efforts are made to try and consult people in hard to reach/ rural areas and that they will continue to try to consult people in accessible ways (M)</p>

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>It was reported that the Citizen Leadership project is newly funded and offers training and awareness to services. Training is delivered by and with people with autism (M, SAQ, SPQ)</p> <p>Several respondents said that training is available in their service for example one respondent said that there is training for teachers and ASN staff and another respondent said that Educational psychology offer sensory training in conjunction with NHS colleagues (SAQ)</p>	<p>46% of respondents said that there was an autism training plan for their service (SAQ) It was reported in the statutory agency questionnaire that there is no coherent training strategy.</p> <p>It was stated that in children services there is ad hoc training however no overall strategic plan, it was said that this requires to be developed and professionals and services require to be made aware of what is available (SAQ)</p> <p>88% of respondents from the statutory agency and service provider questionnaire said that there were further autism related training needs within their organisation (SAQ, SPQ) Some respondents also said that specialist training is required in adult services. It was highlighted that there has been a change in the structure of the Community care department which has resulted in</p>

		a change in the training that is available from NHS (SAQ)
People/professionals who understand	Some respondents highlighted that individual professionals make a difference to the experiences people have of services. One respondent said that "personalities not policies have helped the person I care for find a volunteer post, equally personalities have prevented him" (CQ) Other respondents said that some professionals are understanding and accommodating such as an individual GP at Elgin Medical Practice and a Social Worker in children's services (C)	It was stated in the carers focus group that an improvement in understanding from GP/ psychiatrist and other professionals is required when the person has a dual diagnosis (C)

Issues for consideration
<p>It was highlighted in the statutory agency questionnaire that there is supposed to be an autism training plan in children services, however it was stated that low priority and funding constraints have been an issue and little is available in practice (SAQ) Furthermore in adult services it was stated that there is no overall training plan (M)</p> <p>Some respondents said that there needs to be an improvement in understanding in all core services (CQ) as well as an improvement in training in education as to assist with early intervention and detection (C, CQ) Some respondents from the carer questionnaire said that training in education should be mandatory (CQ)</p> <p>Respondents from the multiagency workshop also said that GP training needs to improve in order to detect autism (M)</p>

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	Some respondents reported that awareness raising is good within education i.e. for teaching staff, auxiliary staff and other professionals that may not be directly involved in educating children (SAQ) Some respondents from the carers focus group noted that health and dental services in schools are excellent (C)	Respondents at the carers focus group felt that there was a lack of understanding of Asperger's Syndrome with some respondents stating professionals do not necessarily recognise that they may need support services (C) Some respondents also stated that there is a lack of understanding and expertise in rural areas (C) Some respondents felt that more awareness and understanding is needed in society (SPQ,CQ, C)
Communication & signposting	No comments	Some respondents felt that there was a lack of involvement and communication between carers and teachers/school (C, CQ)

Issues for consideration

Respondents noted that awareness raising needs to improve in all core services and needs to be mandatory (CQ, C) ensuring that all core services understand how autism relates to their service (SAQ) In particular some respondents mentioned that autism understanding in hospitals, inclusive of GPs and health reception staff needs to improve with regard to understanding the environment that people with autism

may need (C)

It was highlighted that raising awareness in society is required (SPQ, CQ, C) as well as raising awareness, understanding and promoting acceptance in schools, inclusive of mainstream, pre-school, FE/HE and amongst peers to assist in preventing bullying (CQ, C, SAQ)

Respondents noted that improvements need to be made in communicating to carers what services are available. Respondents also felt that communication throughout education between school and parents, inclusive of pre-school and FE, needs to improve (C, CQ) Respondents also felt that communication between services for example between child and adult services, between education and health need to improve as well as an increase in family involvement (C)

Some respondents felt that understanding of Asperger's Syndrome needs to improve (CQ)

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	Respondents highlighted that accessible information can be found via the Moray council ASD web page. The ASD partnership board which includes carers, people with autism, LA, Health and service providers were also said to be updated and consulted at quarterly meetings (M) 62% of respondents said that their organisation made	Some respondents in the multiagency workshop noted that information regarding children's services needs to be improved (M) Respondents from the carers focus group noted that there is a lack of information on what is available in adult services and it was said that support is required to access information as it was said that families have to source all

	<p>information accessible about available services (SAQ)</p> <p>50% of respondents said that there was a clear point of contact in their local area for people enquiring about autism services (SAQ)</p>	<p>information independently (C)</p> <p>It was stated that Self-Directed Support (SDS) is a compulsory approach in Moray (M) From the carer questionnaire responses it was highlighted that 27% of respondents said that they had received information about SDS (CQ) 10% of respondents said that the person they care for uses SDS (CQ)</p>
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Issues for consideration
<p>Some respondents said that information is available but requires development, needs to be more accessible and autism specific. It was stated that the ASD partnership board aims to address this (M, SAQ)</p> <p>Some respondents felt that more knowledge is needed on what services are available and how to access them and that improved communication between services is required in order to address this (SAQ) with some respondents stating that more information on the sensory needs of people with autism is needed (SPQ)</p> <p>Respondents from the carers focus group said that a clear point of contact and a drop in centre for advice and information is needed (CQ) including more support and information from the LA on what options are available i.e. Schooling options, adult service options (CQ, C)</p> <p>Some respondents also highlighted that partnership working, listening and sharing information between LA and health board areas needs to improve i.e. in situations where the family move out of the LA area (CQ, C)</p> <p>Respondents from the carers questionnaire and carers focus group said that there needs to be more support for carers, siblings and people with autism in the form of support groups, resources and opportunities to speak to someone for information and advice (CQ, C) and more</p>

family involvement in communication and decision making (C)

In the Moray adult ASD strategy it states that the aim is for the development of the one stop shop to be the clear point of contact for people with autism (SAQ, M)

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>Respondents reported a mixed experience of diagnosis. Four respondents noted a good experience of the diagnosis process. Some stating " very slow process but thorough" (CQ) One parent noted that the diagnosis process was made easier by a professional who had knowledge and expertise of autism (CQ) Other respondents said that the diagnosis process was "very long and challenging to get answers" (CQ) with some respondents reporting a lack of prompt post diagnosis support and signposting (C, CQ) "straightforward to be diagnosed but no support or additional information offered" "Isolating experience" (CQ)</p>	<p>Respondents from the multiagency workshop stated that the diagnosis service needs to improve; highlighting the need for GPs to be trained in order to detect autism (M) Respondents in the multiagency workshop said that there is a diagnosis pathway for adults which people can be referred to for a private diagnosis. However it was highlighted that GPs may not be aware of this pathway and may not be trained or skilled to know the signs of autism in order to refer to this pathway (M)</p> <p>Some respondents noted that the wait for a diagnosis needs to be addressed (C, CQ) One respondent said that "I had to fight for 26 years" another respondent noted that they "fought for 2 years to get a diagnosis" (CQ)</p> <p>Some respondents from the statutory agency</p>

		<p>questionnaire said that information from referrers during the diagnosis process needs to improve (SAQ)</p> <p>It was highlighted that an improvement in consistency between LA areas is needed with one respondent stating that follow up services ceased when they moved LA area (CQ)</p>
Interventions (universal) for all services	<p>Moray Interagency Development Assessment and Support (MIDAS) was reported to be a positive experience for families. However this service stops before primary school age. Respondents said that funding is required in order to sustain and develop this service and provide on-going support post pre-school age (M)</p>	No comments
Early Intervention approach	No comments	No comments
Multi-Agency/Partnership/Pathway, Communication and Co-ordination of services	<p>Respondents noted that if an adult has a dual diagnosis e.g. autism and LD or autism and MH then the pathway works and they are likely to get a service (M)</p> <p>100% of respondents said that they took a multiagency approach in their area (SAQ) It was stated that there is some evidence of partnership working, however this is not strategic (M)</p>	<p>When asked if there were any barriers to working effectively with other agencies statutory agency respondents noted time constraints, local resources, lack of autism understanding and staff shortages (SAQ)</p> <p>When asked if there were any barriers to working effectively with other agencies service providers noted funding, questions over whose remit/responsibility autism is and recognition of service users with high</p>

		<p>functioning autism and Asperger's (SPQ)</p> <p>Respondents in the multiagency workshop said that it was not always clear if it was child or adult services that ascertain responsibility between the ages of 16-18 (M)</p>
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Issues for consideration
<p>Respondents noted that the pathway is not consistent (SAQ.) It was highlighted that a multidisciplinary pathway needs to be developed for those with autism and with no LD/MH. It was said that an Adult diagnosis pathway is the key priority and will be the most challenging and that support is required to achieve this. Moray used to have an adult pathway called 'Aspire' which ceased due to funding (SAQ, M)</p> <p>Respondents noted that in children's services the multiagency pathway also requires development stating that the point of contact in children's services varies (SAQ)</p> <p>Respondents felt that more support is needed for carers in seeking and during the diagnosis process and for carers to be listened to (CQ) It was also highlighted that during diagnosis involvement from all core services is required (CQ) as well as an improvement in multiagency working between core services and health (M)</p>

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?
Environment including sensory	No comments	Respondents from the carers group felt that the hospital environment was unsuitable for people with autism for example respondents said that there is no quiet area available and not all staff are aware of autism (C)
Reasonable adjustments to accommodate autism	No comments	Respondents from the carers focus group also highlighted that the environment and layout in school does not always meet the needs of people with autism(C)
Service Responsibility including lack of service for people with Asperger's and high functioning autism	No comments	Some respondents in the service provider questionnaire felt that there was a need for a greater recognition of the needs of people with high functioning autism and Asperger's Syndrome (SPQ) It was highlighted in the carer focus group that the eligibility criteria is a barrier for accessing day services as people with Asperger's Syndrome fall between services (C)
Criminal Justice including Police/ Autism Alert Card	Grampian have recently launched an autism alert card in partnership with The National Autistic Society (NAS), Autism Initiatives, Grampian Autistic Society, NHS, police, G4S, Aberdeenshire, Aberdeen city and Moray.	Some respondents were not aware of the autism alert card and some respondents were not aware of how to access the autism alert card (CQ) Some respondents felt that awareness in criminal justice

	This was launched in November 2013 (NAS website)	services needs to improve (C)
Education/Further Educations – including pre-school/mainstream and autism specific	<p>Respondents reported mixed experiences in education. Some respondents noted that integration into mainstream worked well, good inclusion, support and communication (CQ, C) Respondents also said that experienced teachers who explain things and listen along with 1:1 support in mainstream school helped (CQ) One respondent noted a good experience in mainstream primary (C) Another respondent reported "lots of support, they were brilliant at nursery" (CQ) It was reported in some cases that the school work with educational psychology and Speech and Language Therapy, however it was said that this does not always work effectively (CQ) Some respondents said that Moray college support has been a positive experience (C)</p> <p>Two respondents reported good experiences with education with adjustments in the classroom being made and helpful teachers (IQ)</p> <p>75% of respondents had a Coordinated Support Plan (CSP) at secondary school, 13% of respondents did not know and 12% of respondents did not have a CSP (CQ)</p>	<p>Some respondents noted that there is a lack of support/facilities and a lack of understanding of ASD and Asperger's in schools. One respondent said that "mainstream primary 1:1 support not suffice" "(C, CQ) "mainstream variable needs not always met" (CQ)</p> <p>Some respondents said that understanding and inclusion in mainstream pre-school needs to improve "attended a mainstream playgroup which found difficult to cope with" (CQ) with other respondents saying that mainstream primary with additional support did not meet needs "everything a battle" (CQ) A lack of funding for 1:1 support in mainstream school was also highlighted as an issue (C, CQ)</p> <p>It was reported that Scottish Autism have a base in Elgin academy however there are limited places for children with autism available (C)</p> <p>One respondent reported "I had to fight through the local MP to get a place in the correct facility" (CQ)</p> <p>45% of respondents said that the teachers and professionals worked well together to meet the needs of the person they care for in primary education (CQ)</p> <p>50% of respondents said that the teachers and</p>

		professionals worked well together to meet the needs of the person they care for in secondary education (CQ)
Employment/ Employability	In the Moray adult ASD strategy it details that the employment support service has a dedicated employment support worker for adults with autism. Respondents from the carers group felt that this was a good start. (C)	It was highlighted that The Moray adult ASD strategy does not cover all autism diagnosis thus employment objectives stated in the strategy are only for those with autism and no LD (C) "I worry about what his future will be, there are hardly any work experience placements available for my son to experience a supported work place" (CQ) More support in seeking employment, more involvement from the job centre and more opportunities for supported work placements, training and employment was said to be needed (CQ,C) "employers and government organisations accepting difference in practical ways rather than just as a policy document" (CQ)
Housing	Respondents said that the housing medical assessment process is well developed, multiagency and recently reviewed and includes the Occupational Therapy service (M, SPQ) It was stated that the Local Housing Strategy and Moray council housing allocation policy are subject to equality impact assessment and a public consultation process as part of community planning framework	Respondents raised concerns of the impact of bedroom tax on the housing environment for people with autism (SPQ) Respondents also highlighted that there is no suitable housing provision for people with Asperger's Syndrome (C) It was also highlighted that there is limited support for families with children 16+ in supporting them to progress toward independence and into suitable accommodation

	(SPQ) One parent noted a positive experience where the LA had found suitable housing that met the families need (C)	(C) and that support was needed to assist people in developing daily living skills to prepare for independent living (C)
Respite		Some respondents said that suitable respite provision is required and that respite provision should be an integral part of transitioning from the family home into suitable accommodation (CQ)
Transport and Rural Issues	No comments	No comments
Autism Specific Services for Children and Adults	One respondent highlighted their experience of Primary school education "given a placement in an autism unit which was a god send"(CQ) It was also reported that the autism education unit in primary education tailored IEP and support to individual needs, staff listened to parents - "not once did I get a phone call to come and take him home, in mainstream school this was a daily occurrence" (CQ)	One respondent highlighted their experience of primary school education "the special needs school my youngest son went to was not really suitable but mainstream refused to have him" (CQ)
Services - Access/Gaps/performance	83% of respondents said that the needs of the person they care for were partially met by their support service, 17% of respondents said that the needs of the person they care for were not met by their support service (CQ)	Some respondents felt that there is a lack of provision, consistency and expertise in rural areas (C, CQ) and that the environment in services such as health was not always suitable (C) One parent noted that waiting times in hospitals was an area of difficulty (C) as well as waiting lists for support

		<p>services (CQ)</p> <p>It was said that there requires to be an increase in person centred working with one respondent highlighting that "services need to spend more time with the person rather than fitting people into a tick box" and another respondent saying that "services need to observe and assess needs and be flexible" (C, CQ)</p> <p>50% of respondents said that the person they care for had a designated social worker (CQ) 58% of respondents said that the person they care for has had their needs assessed (CQ) 36% of respondents said that the person they care for had their needs regularly reviewed (CQ)</p> <p>Respondents noted issues in gaining access to a CSP, carers assessment and a social worker with one respondent reporting that it is a "fight to get support from social services" (CQ)</p>
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Issues for consideration

Respondents felt that care and support provision needs to improve for example more recreational facilities, social clubs and opportunities for all ages and abilities (CQ, C) It was also said that more opportunities to integrate day services into the community is required (CQ) as well as more opportunities in the community to be safe and included (CQ)

A gap in services for people with autism and no LD and Asperger's Syndrome was highlighted (SPQ) as well as a gap in adult services provision

(CQ, C)

It was highlighted that there needs to be more understanding, support and communication in education “tailoring education to the individual neither forcing mainstream or specialist education onto the child” (CQ)

It was said that more service provision and support is required locally in rural areas with respondents highlighting that services are concentrated in Aberdeen city (CQ)

Respondents highlighted that an improvement in the hospital environment i.e. a waiting room/quiet area would be beneficial as well as ensuring all hospital staff, including reception staff have an understanding of autism (C) It was also said that when professionals access health records in hospitals and GP surgeries an autism logo should flag up on records to ensure autism awareness and recognition of needs (C)

It was also said that commitment is needed to put in services at a preventative level (SAQ) and an improvement in facilities in Moray in order to meet the aims of the Autism National strategy (SAQ)

It was raised that there requires to be more support and opportunities for people to get into appropriate employment (CQ, C)

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	It was highlighted that the local Advocacy service currently covers health and social care. There is not an advocacy service that covers education, this was said to be required by respondents (C) Some respondents also said that an advocacy service for adults would be beneficial (C)

Issues for consideration

Respondents said that an Advocacy service specifically for education is required and an autism advocacy service for adults (C)

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>In the statutory questionnaire it was reported that the Educational psychology service supports pre-school, secondary and post school transitions (SAQ) and that a multi-agency approach to transition starts at age 14 and that adult services are involved (SAQ) with involvement from a Transition officer who works with people leaving school (SAQ) as well as the children and families team actively planning into adulthood (SAQ)</p> <p>Respondents from the carers questionnaire noted mixed experiences with transition some noting good transition between primary and secondary "Speyside high have a system that can gradually ease person into whatever comes next" (C) Other respondents noting that despite input from educational psychology service transitions are still difficult (CQ) "hard battle" (CQ)</p>	<p>Respondents noted that transitions in education need to improve. (C) Respondents noted that transition support from secondary to adult life needs to improve i.e. early involvement needed to assist into FE/employment (CQ, C) with respondents highlighting that opportunities post school are limited (C) One respondent said that they "Thought that services were very good until transition to adult services and very little now available" (C) It was also said that access to a Social Worker needs to improve with respondents highlighting that to receive transition support you need a Social Worker (C) Respondents also noted that communication and more family involvement during transitions is required (C)</p> <p>Some respondents also highlighted that there is a lack of statutory involvement in transitions to pre-school (C, CQ)</p>

Issues for consideration

Respondents said that transition guidelines for children and adult services requires one integrated policy and that child and adult partners are on board with this (M) with post school transition to be considered in a multi-agency way (SAQ) with early communication/support with FE

(CQ)

Respondents reported that transition to primary was a "fight for support" and that an equal partnership between family and education is needed (CQ) as well as a supportive and proactive multiagency approach from schools and other professionals and services during transitions (CQ)

Respondents said that a key worker during transition would help (CQ) or access to a Social Worker during transitions (C)

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/>