



Shetland Islands Council



Shetland's Autism Spectrum Disorder Strategy 2016 -2021



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Shetland's Autism Spectrum Disorder Strategy 2016 - 2021

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1. EXECUTIVE SUMMARY

Scottish Government published The Scottish Strategy for Autism in 2011, making Autism a national priority. The national strategy sets out the government's vision for improvements to services for people with autism spectrum disorder, their families and carers, over a 10 year period.

Shetland's Autism Spectrum Disorder Strategy 2016-2021 has been developed with a range of key stakeholders, and we have identified six local goals, which will inform the development and improvement of local services for people with Autism Spectrum Disorder (ASD) in Shetland.

Our Local Goals:

1. Awareness Raising and Workforce Development

People employed across all sectors will recognise the unique needs of people with ASD. We will work to ensure that clear information is available to people with ASD, their families, and carers, regarding local services available to them.

2. Assessment and Diagnosis

There will be a clear pathway for the assessment and diagnosis of ASD, for both children and adults. This will include signposting to appropriate post diagnostic supports.

3. Active Citizenship

People with autism will have opportunities to engage in meaningful activity throughout the lifespan, enabling them to develop new skills and maximise their potential for independence.

4. Transition

Transitions at key life stages will be planned and managed well for people with ASD, particularly for those moving between children and adult services.

5. Support for Families and Carers

Carers will be recognised as equal partners in providing care and support to people with ASD.

6. Employment

People with ASD should be supported to access employment, and there must be a clear pathway for this.

"This Strategy gives us a clear direction for children and young people with autism across Shetland."

Helen Budge, Director of Children's Services



"Achieving our local goals will make a positive difference to people's lives. The Strategy for Shetland will drive improvement to ensure that we do our very best for our community."

Simon Bokor-Ingram, Director Community Health & Social Care



2. INTRODUCTION

The Scottish Government published the Scottish Strategy for Autism in 2011, setting out the governments vision that:

'Individuals on the autism spectrum are respected, accepted and valued by their communities and have confidence in services to treat them fairly so that they are able to have meaningful and satisfying lives'

The 10-year strategy identifies 26 recommendations for action at national and local levels, recognising that people with autism have unique needs. These recommendations are far reaching, and consider the needs of people with autism across the whole spectrum, and throughout the lifespan. In addition to the recommendations, the strategy identifies ten indicators of best practice in the provision of autism services (see table 1).

Shetland's Autism Strategy sets out the priorities and strategic direction for the development and improvement of local services for people with autism, their families and carers.

Terminology

Autism Spectrum Disorder is used throughout this document, and includes Asperger Syndrome and childhood autism. Some people prefer to use Autism, or the word 'condition' rather than 'disorder,' however for the purpose of this document, Autism Spectrum Disorder is used to fit with diagnostic terminology.

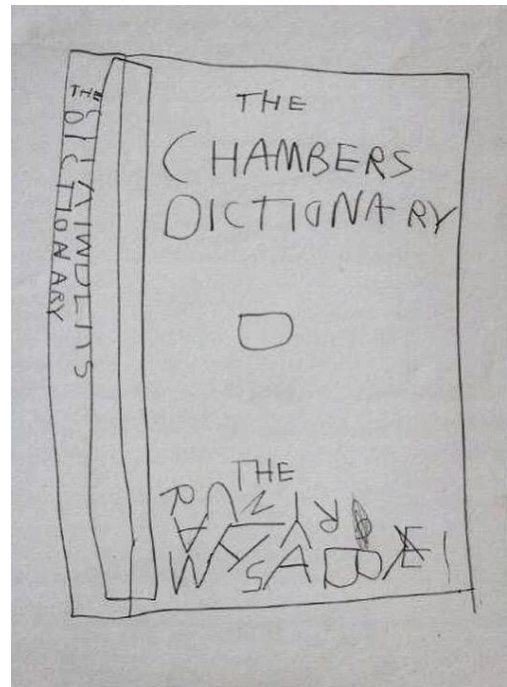
No.	Ten indicators for Best Practice (table 1)
1.	A local autism strategy developed in co-operation with people across the autism spectrum
2.	Access to training and development to inform and improve understanding of Autism Spectrum Disorder (ASD) amongst professionals
3.	A process for ensuring a means of easy access to useful and practical information about ASD
4.	An ASD training plan to improve the knowledge and skills of those who work with people who have ASD
5.	A process for data collection which improves the reporting of how many people with ASD are receiving services and informs the planning of these services
6.	A multiagency care pathway for assessment, diagnosis, intervention and support
7.	A process for stakeholder feedback to inform service improvement and encourage engagement
8.	Services that can demonstrate that service delivery is multi-agency and coordinated and targets the needs of people with autism
9.	Clear multi-agency procedures and plans to support individuals through major transitions at each important life stage
10.	A self-evaluation framework to ensure best practice implementation and monitoring

Table 1: 10 Indicators of Best Practice (Scottish Government 2011)

3. WHAT IS AUTISM SPECTRUM DISORDER (ASD)?

Autism is a lifelong neurodevelopmental disorder commonly referred to as autism spectrum disorder (ASD). ASD affects people differently with some individuals being able to live independently, while other will need a lifetime of specialist support.

ASD affects how people communicate with, and relate to, other people. It also affects how they make sense of the world around them.



"It makes me more of a loner. I am antisocial; I can't easily cope with too many human-to-human integrations. I find it difficult to process all that verbal and non-verbal information. It's a bit like a PC, you can run your OC under Windows and you select four applications to use. Then you spend ages waiting while your computer is trying to sort out which of these tasks it is going to work on and for how long. Then, it shares out the processor time on a basis that cannot prioritise. The upshot is that I can only cope with things on a one-to-one or small group basis, and I don't know how to evaluate and prioritise things"

David Nicholas Andrews - <http://www.angelfire.com/in/AspergerArtforms/autism.html>

Wing and Gould (1979) first described autism as a spectrum disorder. ASD affects each individual in a different way, although all people with ASD will experience difficulty in three areas of functioning. This is sometimes referred to as the triad of impairments and means people may experience problems with the following:

- Social communication – may include difficulty in processing verbal information, understanding and using language, and tone of voice, body language, facial expressions, gestures and articulating feelings.
- Social Interactions – may include difficulty understanding social behaviour and boundaries, personal space, making eye contact, expressing emotions, understanding others emotions, interpreting the actions of others, understanding humour, or showing interest in others views and affects the ability to interact with other people.
- Behaviour and Sensory processing (social imagination) – may include difficulty with sensory processing, may feel more comfortable in set routines and/or repetitive behaviours, develop special areas of interest, and have difficulty in unfamiliar situations, predicting what comes next, and understanding danger, thinking and behaving flexibly.

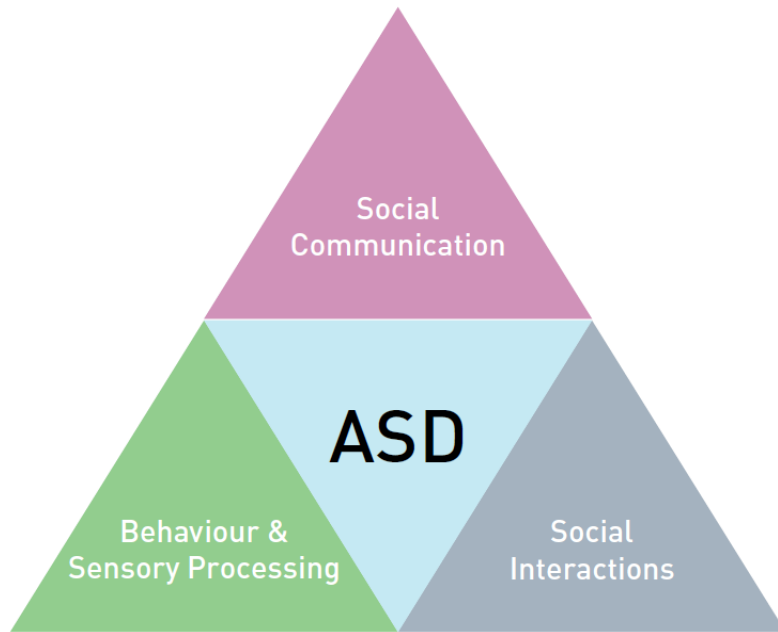


Figure 1: Autism Spectrum Disorder triad of impairments

The most significant area of difficulty for people with autism spectrum disorders is social interaction. This is particularly relevant for people who are diagnosed later in childhood or adult life, as many people learn to compensate for difficulties with social communication or imagination, but the social interaction impairment is still evident even though it may be shown in more subtle ways. Many people with Autism Spectrum Disorder have a co-existing (or comorbid) medical condition such as a learning disability, epilepsy, or other medical problem, which affects their quality of life.

The Scottish Strategy for Autism: Menu of Interventions (Scottish Government 2013) identifies 14 main challenges encountered by people with Autism Spectrum Disorder and their families (see figure 2).

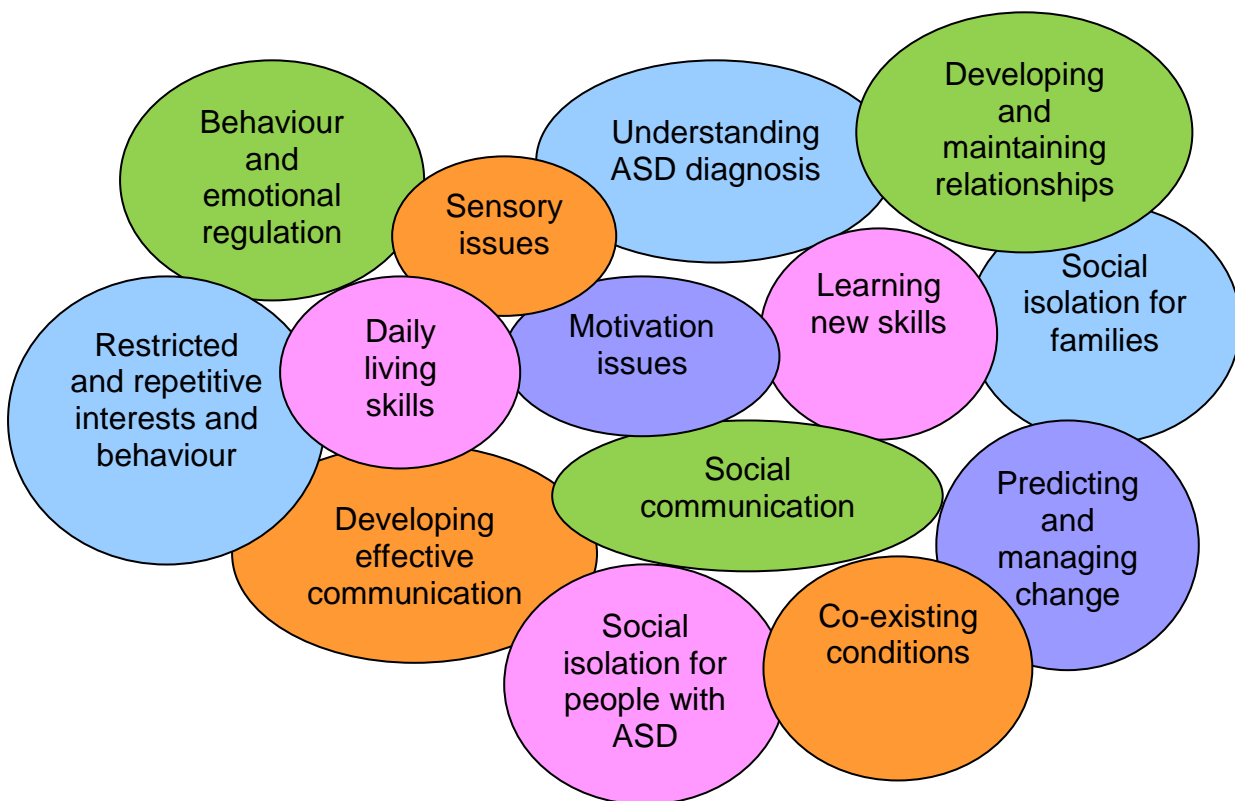


Figure 2: 14 Challenges that can impact on people with ASD and their families

4. PREVALENCE OF AUTISM SPECTRUM DISORDER IN SHETLAND

The national prevalence of autism in children is rising yearly. In 2003 it was reported to be 1 child in 163, 10 years later in 2013 it was reported to be 1 child in 67¹.

The National Autistic Society estimates that approximately 1.1% of the UK population or 700,000 people have autism. Based on 2011 census figures the prevalence in Scotland is as follows:

Population of Scotland: 5,295,400

Prevalence of Autism: 58,249

(National Autistic Society, 2013)

It was estimated that in 2012 there were approximately 202 people in Shetland with Autism, based on a population of 22,500 (National Autism Services Mapping Project: Shetland Council Service Map 2013). Local statistics showed a much lower proportion of people known to statutory services as having Autism Spectrum Disorder, which suggests that there may be people with ASD who do not have a diagnosis, and are not known to the local authority living in the community.

Data collection is an issue nationally as there are no reliable statistics specific to ASD for children and adults. Data is collected in schools regarding the numbers of pupils with additional support needs (ASN), which can include a wide variety of issues. The Scottish Consortium for Learning Disability (SCLD) publishes annual statistics regarding the numbers of adults with learning disabilities (LD), including those with ASD, who have been in contact with local authorities in the past three years, but there are no reliable national statistics regarding the total number of individuals with ASD.

Autism Spectrum diagnosis				No AS Diagnosis	Not known	AS diagnosis as % of all adults	All adults
Classical Autism	Asperger's Syndrome	Other AS diagnosis	Total with AS diagnosis				
28	13	0	41	33	80	26.6	154

Figure 3: Adults with Learning Disabilities or ASD known to Local Authority in last three years (SCLD 2015)

5. THE NATIONAL CONTEXT

The Scottish Government's policy direction is set out through three interlinked strands of Vision, Values and Goals.

Vision

“Our vision is that individuals on the autism spectrum are respected, accepted and valued by their communities and have confidence in services to treat them fairly so that they are able to have meaningful and satisfying lives”

The Scottish Strategy for Autism Scottish Government 2011

¹ Data Source: www.scotland.gov.uk/Topics/Statistics/Browse/School-Education/dspupcensus18

Underpinning Values

- **Dignity:** people should be given the care and support they need in a way which promotes their independence and emotional well-being and respects their dignity
- **Privacy:** people should be supported to have choice and control over their lives so that they are able to have the same chosen level of privacy as other citizens
- **Choice:** care and support should be personalised and based on the identified need and wishes of the individual
- **Safety:** people should be supported to feel safe and secure without being over-protected
- **Realising potential:** people should have the opportunity to achieve all they can
- **Equality and diversity:** people should have equal access to information assessment and services. Health and social care agencies should work to redress inequalities and challenge discrimination

(Scottish Government 2011)

People with ASD expect to have the support of professionals working together in their best interests to make these values a reality.

Goals

The Scottish Government has set out the following high-level goals in the Scottish Strategy for Autism, and a timeframe for achieving them, in order to benchmark progress towards delivering on the government's vision.

Foundations: by year 2:

1. Access to mainstream services where these are appropriate to meet individual needs
2. Access to services which understand and are able to meet the needs of people, specifically related to their autism
3. Removal of short term barriers such as unaddressed diagnosis and delayed intervention
4. Access to post-diagnostic support for families and individuals (particularly where there is a late diagnosis)
5. Implementation of existing commissioning guidelines by local authorities, NHS and other relevant service providers

Whole life journey: by 5 years

1. Access to integrated service provision across the lifespan to address the multi-dimensional aspects of autism
2. Access to appropriate transition planning across the lifespan
3. Consistent adoption of good practice guidance in key areas of education, health and social care across local authority areas
4. Capacity and awareness-building in mainstream services to ensure people are met with recognition and understanding of autism

Holistic personalised approaches: by 10 years

1. Meaningful partnership between central and local government and the independent sector.
2. Creative and collaborative use of service budgets to meet individual needs (irrespective of what the entry route to the system is)
3. Access to appropriate assessment of needs throughout life

4. Access to consistent levels of appropriate support across the lifespan including into older age

Links to other National and Local Drivers

[The Keys to Life: Improving Quality of Life for People with Learning Disabilities, 2013](#)

[National Health and Wellbeing Outcomes 2015](#)

[Shetland Partnership: Our Community Plan, 2013-2020](#)

[Integrated Children and Young People's Services Plan 2014-17](#)

[A Guide to Getting It Right for Every Child, 2012](#)

[Commissioning Services for People on the Autism Spectrum: Policy and Practice Guidance 2008](#)

[The Autism Toolbox: An Autism Resource for Scottish Schools, 2009](#)

[Caring Together: The Carers Strategy for Scotland, 2010-2015](#)

[Self Directed Support: A National Strategy for Scotland 2010](#)

[Supporting Children's Learning Code of Practice \(revised edition\) 2010](#)

6. LOCAL NEEDS ANALYSIS

Shetland is a rural island community in the north east of Scotland, comprising of a number of islands linked by overland crossings and interisland ferry services. Shetland Islands Council and NHS Shetland provide most statutory services in the islands. The Children's Services Directorate of the Council provides Education, Children and Families Social Work and Social Care services including respite and short breaks for children.

The integrated Community Health and Social Care Directorate of NHS Shetland and the Shetland Islands Council includes a range of services for adults and some for children. Due to the relatively small population, people with ASD tend to access services that also support people with a range of other needs, such as having a learning disability; there are limited specialist ASD services. The needs of the people of Shetland are met in their local communities wherever possible, and more specialist services are commissioned outwith Shetland as a last resort. This requires local services to work in a flexible and creative manner to respond to changing needs of the local population.

The model of assessment for both children and adults is strengths based, and outcome focussed in its approach. For Children, Getting it Right for Every Child (GIRFEC) Child's Plan is the multi-agency assessment, and the Barnardos Outcomes Framework is used to measure individual outcomes. For adults, Shetland's Single Shared Assessment process is known as With You For You, and the assessment tool is called 'Understanding You.' Assessments are conducted in a person centred manner, and focus on supporting people to achieve their personal goals.



6.1 Autism Mapping Results

A National Mapping Project was carried out across Scotland to gather information regarding services available for people with ASD at a local level, and to establish a national picture informing future developments, and investment of Scottish Government funding.

The 'National Autism Services Mapping Project: Shetland Islands Council Service Map' was produced in September 2013, and presents a snapshot of services for people with autism in Shetland. The project gathered data using a desk based research exercise (looking at policies and procedures), issued questionnaires to relevant stakeholders and ran a series of workshops conducted in Lerwick, Shetland:

- 25 people attended a multi agency meeting as part of the mapping project including representatives from health, education, social work, Disability Shetland, day services, family services, Supported Living and Housing services, library services, early years services and respite and short breaks.
- 5 carers attended a workshop for parent carers
- Workshops for people with autism were offered by videoconference, but no one signed up for these.

The results from the mapping project are limited in terms of being representative of the views of people with ASD, and their parents or carers. The results of the mapping project are attached as Appendix 2.

There are some areas of good practice locally in the provision of support for people with ASD. However, we recognise that there are some vulnerabilities and areas for improvement, including:

- Difficulty getting a diagnosis of ASD
- Difficulty getting the right support and/or a lack of clarity regarding how to access it
- Specialist knowledge tends to revolve around individuals who have a special interest rather than a designated role for people with ASD

7. LOCAL GOALS

Following a review of information available locally and an evaluation of the services currently provided, we have identified six goals for Shetland. These are summarised in the table below, and there is more detailed information about each of them in the subsequent sections.

1. Awareness Raising and Workforce Development

People employed across all sectors will recognise the unique needs of people with ASD. We will work to ensure that clear information is available to people with ASD, their families, and carers, regarding local services available to them.

2. Assessment and Diagnosis

There will be a clear pathway for the assessment and diagnosis of ASD, for both children and adults. This will include signposting to appropriate post diagnostic supports.

3. Active Citizenship

People with autism will have opportunities to engage in meaningful activity throughout the lifespan, enabling them to develop new skills and maximise their potential for independence.

4. Transition

Transitions at key life stages will be planned and managed well for people with ASD, particularly for those moving between children and adult services.

5. Support for Families and Carers

Carers will be recognised as equal partners in providing care and support to people with ASD.

6. Employment

People with ASD should be supported to access employment, and there must be a clear pathway for this.



7.1 Awareness Raising and Workforce Development

The Council and NHS currently deliver a range of training to staff that support people with ASD, however the procurement of training lacks coordination. A number of frontline staff across services for children and adults received National Autistic Society accredited SPELL and TEACCH training. Education staff have also received introductory training in using the Autism Toolbox, facilitated by Autism Network Scotland. We need to review and evaluate the training we currently provide against the NHS Education Scotland 'Optimising Outcomes Framework,' and establish the knowledge and skills required at each level of the organisation, ensuring procurement of appropriate training to meet the training and development needs of staff in a sustainable and coordinated way.

The Optimising Outcomes Framework identifies four levels of knowledge and skills, as follows:

1. Autism Informed: Essential knowledge and skills required by all staff in health and social care
2. Autism Skilled: Staff with direct and/or frequent contact, or roles with high impact
3. Autism Enhanced: More regular or intense contact with individuals with ASD. Role focuses specifically on autism, provides specific interventions for autism or manages the care or service for individuals on the spectrum.
4. Expertise in Autism: Highly specialist knowledge and skills. Those with a specialist role in the care, management and support of people on the spectrum and their carers.

We will seek to establish a network of Autism Champions across services in both the statutory and voluntary sector, to act as a point of contact for enquiries relating to ASD, and to disseminate information to teams across organisations.

We will also engage with Shetland College UHI to offer accredited qualifications in ASD for staff working across Children and Adult Services.

7.2 Assessment and Diagnosis

The Scottish Intercollegiate Guidelines Network (SIGN) recommends a multi-disciplinary approach to assessment and diagnosis of autism spectrum disorder. The assessment should include a detailed history of the individual's development, direct clinical observations, and take account of how the individual behaves in other situations. Some specific autism or language assessments may also be carried out, for example, ADOS 2 (Autism Diagnosis Observation Scale, 2nd edition).

The ASD Strategy seeks to ensure there are clear diagnostic pathways for both children and adults, and that post-diagnostic support is available for those who need it. We have subdivided this section to reflect the different routes for child and adult diagnosis and support.

Children's Diagnostic Pathway

Following the implementation of the Children and Young People (Scotland) Act 2014, all children and young people in Scotland have a Named Person, who will usually be a Health Visitor or a promoted teacher when the child starts education. The Named Person provides a consistent approach to supporting children and young people's wellbeing, giving access to advice and support for families.

We will ensure that Health Visitors receive training to recognise early signs and symptoms of ASD, and how to refer on for more specialised involvement, and that teaching staff have access to an appropriate level of training following a mapping exercise using the 'NES Optimising Outcomes Framework.'

The Education (Additional Support for Learning) (Scotland) Act 2004 and accompanying code of practice provide a framework for identifying and addressing the additional support needs of children and young people who face barriers to learning. If it is felt that an ASD assessment is required, the local assessment team will carry out the assessment. The team consists of Speech and Language Therapy, Educational Psychology, GP with a Special Interest in Child Health, and a visiting Consultant Paediatrician. There may also be input from Education Outreach Group and the Child and Adolescent Mental Health Service.

The EarlyBird Plus Programme is run as a post diagnostic support group for parents of children aged 4-8 years, diagnosed with ASD. Due to small numbers of children diagnosed locally, the programme runs when there is a requirement. There is a range of other supports available locally for children and young people. Children and young people with ASD have their needs identified through the Getting It Right For Every Child (GIRFEC) process, and support is tailored to meet the needs of the child and their family.

Adult Diagnostic Pathway

We will seek to ensure that diagnosis is available for those who require it, in a timely manner and provided as close to home as is possible. Currently, adults who do not have a diagnosis of ASD may be referred on for assessment by their GP. This may involve the adult having to go off island for an assessment on mainland Scotland, as there are not sufficient services available locally.

Adults who may require community care services are entitled to have their needs assessed in accordance with section 12A of the Social Work Scotland Act 1968. The local authority has a duty to provide services to meet an adult's eligible care needs in accordance with local and National Eligibility Criteria. Carers of adults are also entitled to an assessment of their needs in relation to their caring role. As such, the lack of a diagnosis should not be a barrier to people receiving the services they require. It is acknowledged however that diagnosis might inform a care plan and support strategies, which would benefit the adult. A formal diagnosis will also ensure individuals receive financial support they might be eligible for, and that appropriate supports or 'reasonable adjustments' are considered by employers, as ASD is recognised as a disability under the Equality Act 2010.

We will also seek to provide clarity regarding the post diagnostic support pathway for people diagnosed with ASD in adulthood, and their families, ensuring they are provided with information regarding services they may be eligible for (e.g. respite and short breaks etc.). We will also establish links with acute medical services (hospital) to ensure that the needs of people with ASD are considered when they are admitted to hospital.

7.3 Active Citizenship

People with ASD can face a range of barriers to everyday activities, and it can therefore be difficult to access social opportunities and various other things other people take for granted. This strategy will aim to ensure that people with ASD receive support to engage in activities that are important to them.

The Council's Supported Living & Outreach and Housing Service provide supported accommodation, and outreach support for people with ASD. There are a number of other services that support people to develop independent living skills, and this support can begin at school, if appropriate. We will seek to ensure that we continue to support people with ASD to live as independently as possible in the community.

There are a number of local services which may be involved in supporting people with ASD to participate in meaningful activities, including Shetland Befriending Scheme, Shetland Community Bike Project, Bridges Project, Shetland College, Moving on Employment Project, and COPE Ltd etc. We will ensure that people with ASD continue to have opportunities to develop skills for independent living, and that the accommodation needs of people with ASD are considered by local housing providers.

Shetland Arts currently support ASN film screenings at the local cinema, and they also provide supported creative activities for people with additional support needs. We will ensure that we work with local partners to promote good practice that already exists in the local community, and raise the profile of inclusive practice to make mainstream services more accessible



7.4 Transitions

When considering 'transition,' the primary focus for practitioners, people with ASD, and their families, is often the point where children move into adulthood. It is important to ensure that this is planned and well managed to achieve the best outcomes for people with ASD. It is also necessary to recognise that there are a number of other important transitions throughout the lifespan.

The Scottish Transitions Forum has produced guidance, which identifies seven 'Principles of Good Transitions' (2013). We will ensure that these principles are embedded in practice locally (see below):



1. All plans and assessments should be made in a person-centred way
2. Support should be co-ordinated across all services
3. Planning should start early and continue up to age 25
4. Young people should get the support they needs
5. Young people, parents and carers must have access to the information they need
6. Families and carers need support
7. Legislation and policy should be co-ordinated and simplified

The Shetland Islands Council has an existing policy supporting transition between Children and Adult Services, which we will review to ensure that transitions are managed effectively and in a timely manner for people with ASD. We will also consider the other organisations involved in supporting people with ASD, and how we support transitions at other key life stages throughout the lifespan.

7.5 Support for Families and Carers

Shetland recognises the valuable contribution that carers make to the support of people in our communities, including those with ASD. A carer is someone who provides unpaid care for a friend or relative who needs his or her support due to an illness, disability, mental health problem or addiction (Scottish Government 2010). Shetland is developing a separate Carers Strategy to recognise the vital role carers have in supporting strong communities and this section will focus specifically on support for people with ASD.

The Education Outreach Group, including the Pre-School Home Visiting Services, have a key role in supporting families, particularly in the early years. Where a need is identified, the Council provides short breaks and respite services to support carers and families of children and adults who have learning disabilities or ASD at Short Breaks for Children or Newcraigielea Services.

Voluntary Action Shetland operate a Virtual Carers Centre, which provides a range of information and advice for carers in Shetland. The website signposts to a number of carers groups which provide a source of support to those with a caring role, as well as providing details of training, short breaks, and financial assistance which may be relevant. See www.shetlandcarers.org for further details.

We will seek to ensure that families and carers of those with ASD have timely access to the right information and advice regarding services and supports for people with ASD.

7.6 Employment

Shetland has established a 5-stage Employability Pathway, which sets out the various stages of support a person has to move through in order to gain sustainable employment. The process will support individuals who have two or more barriers to employment, and may include adults who have ASD.

There are a number of supported employment placements available locally, some of which are commissioned by the Shetland Islands Council. These placements enable people to develop skills, which may result in them, to move into sustainable employment at a later stage. There are also volunteering opportunities, and work experience placements supported by the voluntary sector.

We will ensure that the unique needs of people with ASD are recognised by staff working in agencies that provide assistance with employment to ensure that there are opportunities to move into sustainable employment where possible. We will also ensure that commissioned services meet, and continue to meet, the criteria for accreditation set out in the Scottish Government guidance, 'Commissioning Services for People on the Autism Spectrum' (2008).

8. THE VIEWS OF PEOPLE WITH ASD, THEIR FAMILIES AND CARERS

In September 2013, a national mapping exercise was conducted to review the services available for people with ASD, and this included consultation with people who have ASD, their families and carers. The number of people involved in the consultation process was low (see section 6.1); however the local results show that people feel services could be planned better at a strategic level, and that there are gaps in local delivery.

We will seek to establish a local autism network, including people with ASD, family members and carers, to contribute to the future development of support for people with ASD in Shetland. Due to the dispersed nature of the population in Shetland, it is important that we use a variety of methods to effectively engage with as many people as possible, and we will therefore seek to use a variety of communications, including social media, to ensure we reach a wide audience.

Shetland Islands Council reviewed the provision of day services for adults with learning disabilities in 2014, and a working group of parents, carers and people who access day services was established as part of the consultation. The group was successful, and we may seek to broaden the remit of this existing group, to act as a reference group for the provision of ASD and learning disability services.

9. MONITORING AND REPORTING

The Autism Spectrum Disorder Strategy will be accompanied by an action plan, which will be reported on a six monthly basis to the Integrated Joint Board and SIC Education and Families Committee.

The Community Health and Social Care Strategic Group will monitor the action plan on a quarterly basis, to ensure that work is progressing in accordance with the agreed timescales.



10. KEY ACHIEVEMENTS TO DATE

Shetland has made a number of achievements in the provision and delivery of services for people with ASD since the Scottish Strategy for Autism was first published. So far we have:

- Established an ASD Pathway Assessment Team for Children and Young People
- Trained staff in ADOS2 (Autism Diagnostic Observation Scale 2)
- Trained staff to deliver the EarlyBird post-diagnostic support program (for parents of children)
- Delivered training to Health Visitors in detecting early signs of ASD (March 2015)
- Autism Network Scotland delivered training to a number of staff from children and adult services in March 2015
- Produced a directory of local autism resources in conjunction with Autism Network Scotland as part of their Menu of interventions Roadshows: <http://www.autismnetworkscotland.org.uk/shetland/>
- Established a Working Group to develop an ASD Action Plan, which will accompany this strategy document, to drive forward improvements to local services.

APPENDIX 1

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Appendix 2

National Autism Services Mapping Project
Shetland Council Service Map
September 2013

National Autism Services Mapping Project

Shetland Council Service Map

September 2013

National Autism Services Mapping Project

Shetland 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.

Key to codes: the following codes indicate the source of the data ie 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

4 Background for your area?

- Scottish Government Audit for People with Autistic Spectrum Disorders (2004) estimated that the prevalence figure for autism in Shetland based on 2003 numbers of people with a diagnosis was 31.2 per 10,000 for children and 5.4 per 10,000 of the adult population. In children this is just below the national rate of 35.3 per 10,000, but with adults it is more than twice the national average rate of 2.2 adults with a diagnosis per 10,000. Returns from Shetland to eSAY³ Statistics 2011 indicates that information about whether or not an adult has a diagnosis of autism was available for 59 out of 136 people known to services. Of the 59 people for whom there was information, 26 had a diagnosis of autism. The Scottish Strategy for Autism (2011⁴) suggests an expected prevalence rate of 90 per 10000 which would suggest the actual prevalence figures for autism in Shetland, going by the 2012 population of 22,500, would be 202.
- Autistic Spectrum Disorder Policy for Children and Young People, Shetland Islands Council Children's Services (2011) sets out 12 Key Priorities to provide autism friendly provision both within and out-with education built on involvement of young people and their carers. Recognition is given to the need for information, guidance, respite and support groups for families, successful transitions in to adult services plus promotion of community awareness and understanding of autism.
- The Better Brighter Future 2011-2014 is Shetland's integrated children's service plan which plans to meet the additional support needs of children through the Getting it Right for Every Child approach.
- With You for You (2010) is the person-centered multi agency approach for the planning and delivery of adult care and support services.
- There is a multi agency autism strategy group with representation from both adult and children services.

³ http://www.sclid.org.uk/sites/default/files/booklet_1_-_learning_disability_and_asd_2.pdf

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

5 What we asked and who responded to us

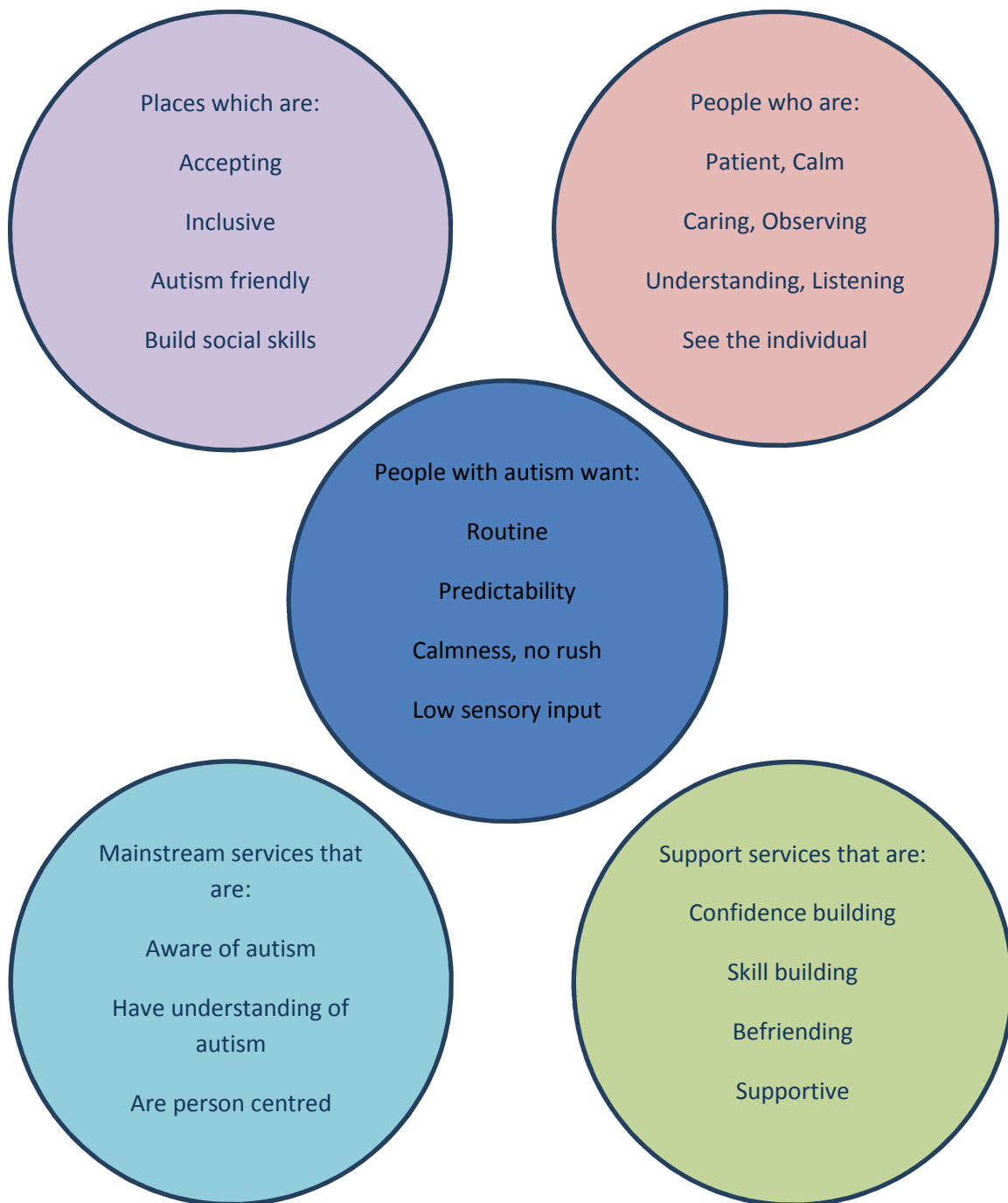
- A desk-based research exercise was carried out into policy in Shetland including autism specific policy as well as wider additional support needs/disability policy across social services, education and housing.
- 25 people attended a multi agency meeting which included people from health, education, social work, Disability Shetland, day care services, family services, supported living and housing services, library services, early years services and respite services.
- 5 carers attended a workshop for parent carers
- There had been an arrangement to meet with a group of people with autism through Disability Shetland, but this was cancelled as Disability Shetland felt the ability range of participants was too wide for the workshop to be accessible. Two opportunities were offered for a workshop by video conference but no one with autism in Shetland signed up for this.
- 7 people from statutory agencies and 1 individual with autism completed online questionnaires from Shetland. No service providers or carers completed questionnaires online. The individual with autism did not include any qualitative data on his/her response.
- The short time scale of the mapping project meant that only one visit was possible and this severely limited opportunities for people to participate.
- The autism strategy group distributed the link to the online questionnaires widely. The low response rate may be for a number of reasons, but given that the 5 carers who took part rated services as good or excellent, it is possible that it is because people are generally satisfied with services that meant they did not feel the need to respond.
- Due to the amount of information from any group in Shetland, this service map provides only a partial picture of services in Shetland. Quantitative information from the online questionnaires across Scotland is included to provide some general information.

The numbers responding is represented in the table below

Focus Groups	Nos	Questionnaire responses	Nos
Multi-agency	18	Multi-agency	7
Service providers	7 *	Service providers	0
Parent/Carers	5	Parent/Carers	0
People with autism	0	People with autism	1

*As many support services are provided in-house it was not always clear whether people were service providers or statutory agency.

6 Carers told us people with autism want:
(No qualitative data available from individuals with autism)



Carers were asked to agree their top three actions points which they would like to see.

Top three action identified by Parents/Carers in (LA)
1 Place for information and carer support
2 More access to respite, including for siblings
3 More opportunities post-school

Specific information relating to Parent/Carers' Issues

	What's working well?	What's not working well?
Parents/Carers as equal partners	In respect of a young person's independence, parent/ carers only involved in planning with permission of young person (SAQ).	No comments were made
Carers/Family Support including groups/listening to carers/carers assessment/named person	The ASD policy (2011) mentions the importance of access to family support groups (P). Carers spoke of a coffee morning where children were catered for and safe, so parent carers were able to chat to one another (C).	No comments were made

The five parent carers were very positive about the services they received.

8 Comments about Community and Social Opportunities

	What's working well?	What's not working well?
Community and social opportunities	<p>The leisure centre (C) library (SAQ) and adult learning (M) are mentioned as accessible community opportunities.</p> <p>A social group for teenagers with autism or ADHD was also mentioned (M).</p> <p>The National picture presented is that there is wide recognition (90% QQ) that social/community opportunities are important.</p> <p>The National picture presented is that support to access social activities is reflected in 90% of care plans (QQ) .</p>	<p>The national picture presented from carers completing these questions is 90% thought children faced social challenges at school, only 50% thought the person they cared had friends in the community and only 34% thought the person was included in the community (QQ).</p>

Issues for Consideration
It was said that people should be patient and understanding as this makes things easier for the carer

9 Statutory and Voluntary Services perspective

25 people attended the multi agency meeting, as indicated below. Most of the service providers listed below were involved in short breaks, respite or day care provision, one was from Disability Shetland.

Agencies attending Focus Groups	Nos
Health	1
Social Work	1
Education	7
Further Education	
Criminal Justice	
Police	
Employment/Employability	1
Housing/building standards/supported living	5
Service Providers	7
Other/environmental health/library/infrastructure	3

Rating where people feel they are with the LA Strategy for Autism where 1 is 'work has not yet begun', 2 is 'made a start', 3 is 'good progress' and 4 is 'completed'.

Good practice indicator	Mean score
A local autism strategy	2
Access to training and development	2
A process for ensuring a means of easy access to useful and practical info about ASD	2
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	3
Clear multi-agency procedures and plans	2
A self-evaluation framework	2

10 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 ASD 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 clear autism Policy and action plan for children's services (P&M).</p> <p>There is a multi agency group which meets regularly to take the strategy forward (P) and there is a link to adult services (M) from his group.</p> <p>The National picture presented is that 78% of NHS staff and 92% of other statutory agency staff sought service user feedback in development of services(QQ)</p>	No lead was identified (SAQ)

Issues for Consideration
Better links between children and adult services (M)

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	There is evidence of awareness raising across the sector, specific service training and NHS /Education had training plans (M&SAQ).	There may be a gap in getting training to the frontline in services outside of health or education (M). Although people receive awareness training they recognise the need for further training (SAQ) and training which is not just for support staff but for all staff (SAQ).
People/professionals who understand	People who are patient and understanding of autism, who observe and listen to understand the uniqueness of the individual; who are calm and able to sort out challenging behaviour from autism, people who genuinely care; these are the people who are able to make a difference (C).	

Issues for Consideration

- A coordinated approach to autism training across the area (M&SAQ)
- Better links to training opportunities (M&SAQ)

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	<p>There is Early Bird and general awareness training in children's services (M) and Adult Learning do awareness raising about Aspergers across the public sector (SAQ).</p> <p>The ASD policy (2011) promotes community wide awareness raising (P).</p> <p>The National picture presented is that appoximately half of service providers thought they had a role in raising awareness (QQ).</p>	<p>There are still some agencies who have a limited awareness of the impact of autism on the individual's life (SAQ).</p>
Communication & signposting	<p>ASD policy (2011) aims to provide the right information and guidance to families (P) and a range of examples of available information was provided (SAQ).</p> <p>Psychology are good at ensuring communication needs are met (M) and other services take a person-centred</p>	<p>Adults would benefit from post diagnostic information (M).</p>

	approach to communication (SAQ).	
Inclusion/Acceptance of autism	There are inclusive evening classes (M).	

Issues for Consideration

- A co-ordinated approach to raising awareness and providing information about local and national support would be helpful (SAQ).
- Improved information is an action in the service plan (M); carers raised their need for more information (C).

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	<p>Social Work collect data; there is data collection within education but there are data sharing issues re sharing with other agencies (M).</p> <p>The national picture presented is that 90% of NHS staff, 94% of other statutory agencies and 87% of service providers said they recorded if service users had autism (QQ).</p>	<p>There may be a lack of consistency in data sharing approaches (M).</p> <p>A concern was raised about the secure GSX email (M).</p>

Issues for Consideration

- The consistency of approach to collection of data
- An approach to resolving information sharing issues

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	Carers reported good pre and post diagnostic support (C). NHS and Learning Disability link around adult assessment (M)	However, there is recognition that there is a gap in securing an adult diagnosis if it is not picked up in school. Adult diagnosis is off-island (M&SAQ).
Interventions (universal) for all services	Various different interventions were mentioned, Moving On, Direction Team and Shetland Befrienders (M).	
Prevention (early intervention) approach	Bruce Family Centre and Disability Shetland listen and respond to need preventing a crisis being reached (C).	
Multi-Agency/Partnership/ Pathway, Communication and Co-ordination of services	<p>Better Brighter Future children's service plan uses the Getting it right approach to additional support services. With You For You is the person-centred approach to providing services for adults (P).</p> <p>Lots of examples of good multiagency working were provided in both children and adult services, between statutory agencies and service providers (M&SAQ).</p>	<p>The multiagency approach works well around individuals but is not planned strategically (SAQ).</p> <p>There were examples given of some agencies which do not seem to engage as well (M).</p> <p>Some families will opt not to have involvement of social work, preferring to seek information and advice only (SAQ).</p>

Issues for Consideration

- Improved information as part of post diagnostic support including information about local services (C).

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	Psychological service input to schools about the sensory needs of autism (M).	In the national data 74% (QQ) individuals with autism completing the questionnaire reported experiencing sensory difficulties at school; 66% (QQ) of these did not receive any help with that.
Reasonable adjustments to accommodate autism	Autism friendly cinema screenings is an example of reasonable adjustment (C).	
Services - Access/Gaps/performance	In terms of services meeting the need of people with autism, the National picture presented is that 26% carers said that needs were fully met, 60% partially met and 14% not met (QQ).	Access to a GP can sometimes be difficult (M).
Service Responsibility including lack of service for people with Asperger and high functioning autism		The multi agency group suggested that services for adults with autism could be improved and that the services for individuals who are high-functioning but still have complex needs are not consistent.

Criminal Justice including Police/ Autism Alert Card	The national picture presented is that only 28% of people with autism had Autism Alert Cards and only 6% of those had used it (QQ).	
Education/Further Educations – including pre-school/mainstream and autism specific	Several mainstream schools were cited by carers as being good (C). A person centred approach is taken to meeting the needs of students in college (SAQ).	There was a suggestion from a Statutory Agency that the information from schools to colleges could be passed on earlier so that individuals could be supported.
Employment/ Employability	Employment services work to support individuals to acquire the skills needed to gain employment or access training. The support offered is person centred and for as long as needed. Potential employers are provided awareness raising (SAQ). Nationally 33% people with autism is said they were in work, of whom 47% had support and 56% enjoyed their work. (QQ)	It was suggested that there is a lack of employment opportunities available particularly outside of Lerwick (M).
Housing	Housing as an organisation has a good understanding of autism (C).	Housing services would like to improve housing for people with autism Shetland wide (M).
Respite	The ASD policy 2011 recognises the importance of respite to families (P). The Laburnum Centre works well providing both respite and life skills development (C).	

<p>Transport and Rural Issues</p>	<p>" I do feel however that the discreet geography and small population of Shetland means that there are opportunities to work productively & imaginatively with other agencies in meeting support needs." (SAQ).</p>	<p>Rurality presents a challenge to delivering the strategy in current economic restrictions (SAQ).</p>
<p>Autism Specific Services for Children and Adults</p>	<p>Spectrum group, Disability Shetland, Bruce Family Centre; Laburnum Centre were all listed as valueable services (M&C). One of the benefits is that these services offers routine and predictability (C).</p> <p>Nationally 66% of service providers were providing a targetted service for people with ASD (QQ).</p>	

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.

Autistic Spectrum Disorder Policy for Children and Young People, Shetland Islands Council Children’s Services (2011) recognises the importance of involving people with autism and their carers.

9.

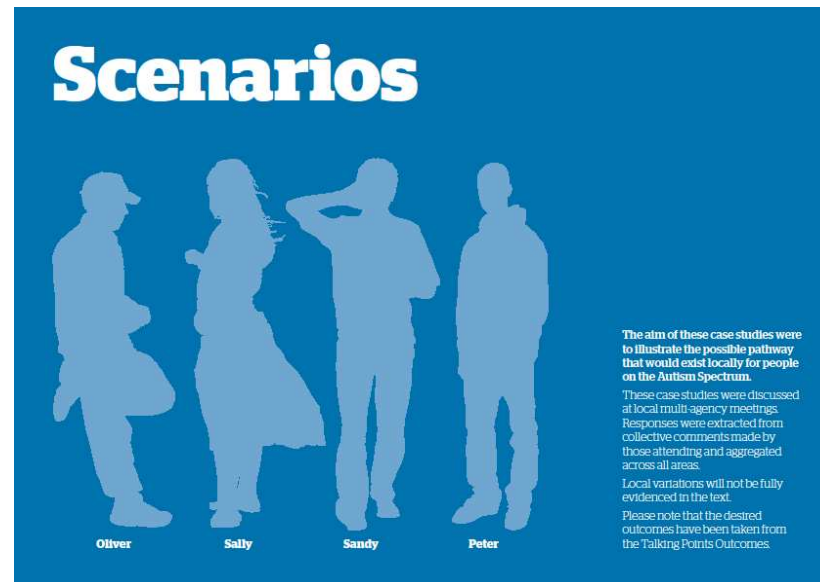
Clear multi-agency procedures and plans which are in place to support individuals through major transitions at each important life-stage.

	What’s working well?	What’s not working well?
Transitions – all major life transitions	<p>The ASD policy (2011) promotes successful transition in to suitable adult service provision (P).</p> <p>The links between school and adult services are robust (M) and liaison with further education good (M&MQ).</p>	<p>Lack of data sharing can make transitions difficult (MQ).</p>

11 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/>