

National Autism Services Mapping Service

Stirling & Clackmannanshire Council Service Map

September 2013

National Autism Services Mapping Project

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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

Prevalence Rates of ASD National

The prevalence estimates in the Public Health Institute of Scotland's (PHIS) ASD Needs Assessment Report (2001³) suggested 60 in every 10,000 people were affected by autism. As part of its acceptance of the PHIS recommendations, the then Scottish Executive undertook an audit of services for people with autism in 2004.

(Audit of Services for people with Autistic Spectrum Disorders Statistical Report)
www.scotland.gov.uk/Resource/Doc/1095/0001881.pdf

Its remit was to provide information for service commissioners on the best available knowledge about autism and current service provision in Scotland, and guidance on how these services might better meet the needs of both children and adults with autism in the future. The intention was to assess the extent to which national prevalence rates could be regarded as a sound basis on which to plan services. It was also the first time that social and health care planners for both children and adult services attempted to quantify the incidence of autism in their locality. Whilst the ultimate analysis carried a number of reservations about the reliability of the findings, acknowledging its patchiness and the likelihood of underestimation, it did provide a much clearer picture than had existed up until that point.

More recent studies suggest that a rate of around 1 in 100 is currently the best estimate of the prevalence in children and adults.

Since the time the survey was conducted, some authorities have built on this data to continue local planning. The Scottish Government now collects data on the number of school children with autism.

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

Prevalence Rates Clackmannanshire and Stirling

The mapping exercise did not ascertain up to date figures for prevalence rates for the total population in the Clackmannanshire and Stirling however, figures outlined in the Scottish Strategy for Autism⁴ estimated the following prevalence rates based on the local authority populations in 2006.

Area	Population	Prevalence Rate
Clackmannanshire	48900	440
Stirling	87810	790

Children and Young People in Education

The Additional Support for Learning and Young Carers – Report to Parliament (Publication Date February 18, 2013⁵) identifies the following figures of children within Education. These figures represent the numbers of children and young people reported as having additional support needs, and those who have a co-ordinated support plan, those who have an individualised educational programme and those who have a child's plan.

	Scotland	Clacks	Stirling
The number of children and young people having Additional Support Needs (Recorded)	117818	1203	1634
The number of children and young people having an Autistic Spectrum Disorder(Recorded)	8,650 7.34% of ASN population	58 4.8% of ASN population	114 6.9 % of ASN population

Autism Action Development Group

There is presently an Autism Action Development Group which has representation from across Clackmannanshire and Stirling. This multi-agency working group will oversee and drive forward the development of the strategy and the local action plan. The group is presently looking to expand its membership to include those services that are not presently represented such as Criminal Justice. Presently there is no autism strategy but work is beginning here and will involve people with autism and their Carers. Given the joint Education and Social Work Services in the area, the strategy will be developed jointly with Clackmannanshire and Stirling. Chris Sutton Service Manager (Strategy) Stirling and Clackmannanshire Councils has been identified as the lead officer on the Autism Strategy.

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

⁵ <http://www.scotland.gov.uk/Publications/2013/02/7808/0>

Policy Context Stirling and Clackmannanshire

A desk based exercise was undertaken to establish whether any strategies or frameworks existed where there was specific mention of autism or ASD:

- In 2009 a Position Statement Report was produced by the Forth Valley Partnership ASD Steering Group. The aim of the report was to assist Forth Valley Partnership respond more appropriately and coherently to the needs of adults with autism, including the majority who do not have a learning disability but who may have distinctive needs. This report identified a number of key considerations to be addressed by partners. The report reached draft stage but was not signed off;
- Stirling's Local Housing Strategy 2012 identified that meeting the needs of people with autism will be an increasing priority for the Council over the next 5 years; (Reference 5.43)
- Forth Valley Integrated Carers Strategy, (FVICS) 2012 – 2015, identified support for carers and young carers through the Autism Strategy Development Fund;
- Clackmannanshire's Psychological Service Development Plan 2010-2013 is working on identifying areas of work where consistency of approach is essential including autism.

Overall while not specifically directed to autism a number of other strategies were identified which had a bearing on carers and people with autism.

- The GIRFEC approach runs through all the work with children, young people and their families carried out across Stirling and Clackmannanshire Councils;
- The Service User and Carer Involvement Strategy, Stirling and Clackmannanshire Social Services, underpins working in partnership with carers and service users;
- The Charter for Carers in Clackmannanshire has been produced by Clackmannanshire Council and NHS Forth Valley in partnership with the Princess Royal Trust for Carers, local carer organisations and carer representatives.

5 What we asked and who responded to us

- 37 people took part in a joint multi-agency workshop, including professionals from Health, Social Work, Education, employment services and providers.
- Workshops for Carers were held in Raploch and Buchlyvie with an additional two being held in Alloa. The workshops were organised with the support of ASN Outreach and Scottish Autism. Local partners contributed to distributing the information on the events. Overall 20 carers took part in the workshops.
- 2 workshops were held in Stirling for young people with autism again with the support of ASN Outreach and Stirling Youth Services. We were unable to hold any workshops for people with autism in Clackmannanshire and this is a gap in the data set which should be taken into account when reviewing the service map.
- 4 On line questionnaires for statutory agencies, service providers, carers and individuals with autism were distributed through known networks in Stirling and Clackmannanshire. Information about the mapping exercises was also posted on local authority websites. 71 people from statutory agencies, service providers, carers and individuals with autism completed the online questionnaires. There were no responses to the statutory questionnaire in Clackmannanshire. One of the reasons for this may have been that some individuals in joint services responded from the perspective of the existing partnership in Education and Social Work across the two local authority areas. However it is another gap that needs to be taken into account when interpreting the information. While some people may have contributed more than once overall there were 153 contributions. ([See Appendix for breakdown](#)).
- Multi-agency workshops asked people to score their area against the indicators; discuss the service response to a number of case studies; indicate the breadth and depth of partnership working and finally summarise what is working well and what might require further action.
- Carer workshops asked people to describe positive factors which contribute to the quality of life for the person cared for; score and comment on service provision and identify things which work well or could be improved and finally to consider their three top action points.
- The workshop for individuals similarly asked people about their quality of life and what would make a difference in their area.
- All national information is taken from the national data and is provided to supplement local data and set it in the context of the national one.
- 1,602 online questionnaires were submitted, 434 from statutory agencies; 189 from service providers; 719 from carers and 274 from individuals with autism.

Focus Groups	Nos	Questionnaire responses	Nos
Multi-agency	37	Multi-agency	16
Service providers	0	Service providers	10
Parent/Carers	20	Parent/Carers	40
People with autism	25	People with autism	5

6 What people with Autism told us

The young people who contributed to the mapping exercise had strong views on the need for awareness raising, rights and more understanding in the community. They also wanted to be able to come together more.

There are a number of developing opportunities for young people to meet through ASN Outreach and Youth Services.

The information in the diagram below has been taken from the comments that the young people attending the workshops made. It illustrates the personal, community and service life that people with autism experience.



NAS Person Diagram FORM Stirling.pdf

	What's working well?	What's not working well?
Quality of Life Outcomes	<p>Young people with Autism attending the workshops described various attributes and indicators of a good quality of life: these were:</p> <p>Trust; Loyalty; Honesty; Respect; Feeling Safe; Consistency; Routine.</p> <p>Young people wanted to do new things, be part of a community with places to go and to have good relationships with family and friends around. They also valued professionals who understood. They described many places that helped them. (See people graph.)</p>	<p>Within the groups young people across all schools identified 3 main issues.</p> <p>Bullying:</p> <p>“Support has been pretty good but little things i.e. bullies aren’t dealt with enough.”</p> <p>“Other pupils make it hell.”</p> <p>“Other people being sarcastic.”</p> <p>Communication:</p> <p>“Don’t feel able to talk to others with autism especially girls.”</p> <p>“Where can I air this point “it’s</p>

		<p>hard to bridge the gap “</p> <p>Being stereotyped:</p> <p>“See the label and underestimate.”</p> <p>“Can be patronised – feel diminished.”</p>
Community and social opportunities	<p>Both Carer workshops and workshops for people with autism identified a range of places which brought community and social activities. An example was the young people attending St Modan's School who run their own social activities on Friday nights.</p> <p>Providers also offer social opportunities. Examples were:</p> <p>Plus, providing support to children to have fun and socialise;</p> <p>Streets Ahead for people with no diagnosis where support is provided to adults who have a learning disability to access social, educational and recreational activities within their local community. M</p> <p>Scottish Autism has recently set up Kinnections a social group for people with autism in Central Scotland. They also have a social activities group who plan social events for wider service user group. SPQ</p> <p>Opportunities for social interaction are included in care</p>	<p>100% of Carers said that the person they care for faced social challenges at primary and secondary school (e.g. making and maintaining friendships).</p> <p>Having things to do was often seen to be very limited in the community. There were limited opportunities for some specialist providers like Plus to meet all the needs of people with autism. C.</p> <p>Evening and weekend opportunities were also limited through traditional support services. SAQ</p> <p>One Carer described her son being an easy target in the community and being picked on and a second Carer said that they often did not go out because of their child's lack of awareness of danger. This increased the whole family's isolation. CQ</p>

Issues for Consideration

Quality of Life Outcomes

- Carers want their family members to have fulfilling and meaningful lives: "Happiness, health, family, love, relationships, career, making a difference." CQ
- "I just want my boy to be happy and healthy and able to live normally that is all I wish." CQ
- Consideration needs to be given to the long term security and future of people with autism and their families with particular regard to the increasing aging population.

Community and Social Opportunities

- Individuals and Carers wanted more opportunities to meet and socialise with others. I/C/CQ
- Social activities for over 16's who were no longer able to access clubs like Kidsclub were also seen as necessary.

More support was required for those individuals who were not able to access established groups because of complex needs. CQ

7 What Parents and Carers told us

Parents and Carers discussed many issues that were pertinent to them and the family members they supported. The word cloud below represents, things Parent/Carers felt contributed to quality of life for the people for whom they cared.



Key to codes: the following codes 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

Specific issues relating to Parents/Carers		
	What's working well?	What's not working well?
Parents/Carers as equal partners	<p>Service providers described the involvement of people with autism and Carers on advisory boards and steering groups. SPQ</p> <p>The established Autism Action Development Group is seeking the representation of people with autism and family Carers on the group. SAQ</p>	<p>Some Carers said there was a lack of consultation generally with them with no clear route for them to have an input on what should happen locally. C</p> <p>One Carer described a situation where despite having quality support from a provider with understanding, she was being forced to change providers to meet procurement contracts. C</p>
Carers/Family Support including groups/listening to carers/carers assessment/named person	<p>Most of the respondents to the statutory questionnaire said that they sought feedback from service users and Carers at an individual level.</p> <p>Statutory organisations and providers both ensure that individuals and their families are involved from the start in care planning using person centred approaches. Examples of how individuals and Carers were engaged included:</p> <ul style="list-style-type: none"> • Taking time to build trust and mutual understanding; • The use of picture mats, graphics as appropriate and the use of family or paid translators if sign 	<p>Carers said that they often felt that they had the total overall responsibility for all aspects of their child despite the number of paid professionals involved and that the pursuit of support was often down to the Carer to manage. CQ/C</p> <p>Parents also reported that there were occasions when they felt decisions were made without looking properly at the specific needs of people with autism and their Carers. CQ</p> <p>"So often we have seen parents thoughts and ideas ignored by professionals who seem to think they know better having learned it all from books!!" CQ</p>

	<p>language is appropriate;</p> <ul style="list-style-type: none"> • Symbols and voice output devices and ensuring the environment is appropriate to needs; • NAS has a support group for parents which provide Carers with a chance talk to each other. SPQ 	
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Within the questionnaires we asked carers what were the main changes they wanted to see happen in their area. We also asked the same question in the workshops. From an analysis of all responses the table below illustrates the top three action points.

Top three action identified by Parents/Carers in (LA)
1 Awareness raising and training across all sectors and the community
2 More support for carers and families
3 More opportunities for social activities for children young people and adults

Issues for Consideration
<ul style="list-style-type: none"> • Generally Carers wanted to see proper consultation with parents and Carers both at individual and group level and recognition that Carers are the experts in care and their opinions are valid. C • There was a need for a parent forum where views could be taken into account. M • Further exploration on how best to involve Carers and individuals with autism at a strategic level would be helpful given that the future development of a local strategy

- should be undertaken in co-operation with people across the spectrum and Carers.
- Carers wanted more support for the whole family including siblings and this was also a need recognised by professionals. CQ/M
 - A general culture of listening to parents would also help. "Health visitors should listen more to the parents and try to give support rather than just saying that it is normal child development." CQ
 - Young people wanted to be able to discuss ASD related issues in their peer group. Many young people are in mainstream school and there is little opportunity to meet with others. I

8 Statutory and Voluntary Services perspective

The table below outlines the representation from organisations attending the multi -agency workshop. Not all attendees identified the local authority (Clackmannanshire or Stirling) where they worked and so the table does not break down this information.

Agencies attending Focus Groups	Nos
Health	5
Social Work	3
Education	7
Further Education	0
Criminal Justice	0
Police	0
Employment/Employability	3
Housing	0
Service Providers	15
Other	4

We wanted to get a sense of where participants would rate their local area with regard to the Indicators of Good Practice. Individuals were asked to score their area/agency using the scoring system below:

1 = you have not yet begun to work on this indicator

2 = you have made a start on this

3 = you have made good progress with this

4 = you have completed work on this

5= don't know

Individuals' scores were tallied and the table below illustrates the mean score

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 autism	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	2
Clear multi-agency procedures and plans	2
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	Presently there is an Autism Action Development Group (Clacks and Stirling) which has been meeting to begin to develop a local autism strategy. The group has representation from the 2 areas and is seeking further representation from specific services not included as yet such as Criminal Justice, Housing and Mental Health. Both Clackmannanshire and Stirling have agreed to pool the budgets provided by the Scottish Government and are seeking to employ an Autism Strategy Coordinator (working title).	While there is a named lead identified for the management of the strategy 86% of statutory and provider responses to the questionnaires didn't know who was leading on autism or thought there was no clear lead.

Issues for Consideration

- Clarity on the strategic lead and an autism champion would improve joined up delivery and partnership of services. SPQ
- In addition, policies and procedures (at agency, Local Authority and Health Board level should be adaptable and flexible to reflect the needs of people with autism. SPQ

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>Both statutory and provider agencies offer a range of training opportunities:</p> <p>Within education there is access to local training and funding for autism certificates/diplomas; M</p> <p>Right Click is a web based training programme offered by Scottish Autism;</p> <p>The Richmond Fellowship is providing Scotland wide opportunities for Carers as a result of funding from the Autism Development Fund;</p> <p>Educational psychologists provide a training programme for schools;</p> <p>Speur Ghlan also provides a range of courses and workshops to parents;</p> <p>Carr Gomm's, 'Introduction to Autism Training', is</p>	<p>While there is a lot of individual training there is no full training plan for autism training. M</p> <p>There were some concerns that support workers were not receiving the adequate training that they needed to work with individuals who had complex needs, for example. C/CQ</p>

	<p>delivered to all new staff at induction;</p> <p>There are DVDs available produced by young people through PLUS.</p> <p>Providers reported that they worked to person centred approaches at all times. SPQ</p>	
<p>People/professionals who understand</p>	<p>Carers and individuals described a range of people who understood. These included family and friends, professionals, services and the community at large. C/CQ/I</p> <p>The quality of a service was seen to depend on the quality of staff.</p> <p>"My son is in a good situation at the moment but that has come about through having parents who have worked hard to ensure it has happened and have been fortunate to have been supported at important times by people who have understood autism and have understood our son's needs and how best to meet them." CQ</p>	<p>However not everyone had the same level of understanding.</p> <p>There was criticism of some health professionals such as Dentist/GPs and paediatricians who lacked experience and provided poor input. C/CQ</p> <p>A lack of understanding of the condition meant that professionals and others were often quick to judge Carers and individuals with autism and often jumped to the wrong conclusions about behaviours. There was also a lack of understanding of the communication support needs of people with autism. C/CQ</p>

Issues for Consideration

All workshops and questionnaires identified training needs. 92% of statutory responses identified that training was required. The list below summarises perceived need:

- Mainstream teachers mandatory trained;
- Training for workers in sport;
- Understanding of sensory needs;
- A core training programme for staff in services;
- Person centred approaches;
- Autism awareness should be rolled out to frontline workers, facilities management and resource planning staff;
- Awareness raising training to all schools;
- Information on Asperger syndrome;
- On-going PG qualifications needed for those closely involved in autism teaching;
- Awareness of the Autism Toolbox;
- Training for parents to deal with challenging behaviour;
- Carers wanted to see more professionals in the Health Service with knowledge of autism. Health Services were one of the first interventions for families and a better understanding in the early years by those who first come into contact with the child was vital. C

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>38% of statutory and provider responses to the questionnaire said they had a role in raising public awareness.</p> <p>One of the roles of Local Area Coordination is to raise the awareness of autism and other disabilities in all forums which includes the community, council, NHS or with 3rd sector. SAQ.</p> <p>Some older Carers said that there was definite improvement in awareness in comparison to the past. CQ</p> <p>One provider spoke of a card explaining about autism that parents use to hand to members of the public when they have a difficult situation with their child. SPQ</p>	<p>However Carers believed that many professionals didn't understand about autism. C/CQ.</p> <p>This was predominantly within mainstream services with Health and Education being mentioned as particular areas where awareness could be improved.</p> <p>The lack of awareness in the public domain was also raised. C/I/CQ</p> <p>In addition, Carers worried about public perceptions when a child demonstrated behavioural problems. Often members of the public would see this as bad parenting. This was difficult to address. C</p> <p>A response by a statutory provider said that while there was recognition that autism knowledge and awareness was a role that needed to be taken up, the current lack of strategic lead meant information was disaggregated and disparate. SAQ</p>
Communication & signposting	There were a number of named points of contacts identified through the questionnaires where	While there is a contact within the Learning Disability team, this does not include support for Asperger

	<p>information was provided: These were:</p> <ul style="list-style-type: none"> • The Local Area Co-ordination Team; • The Integrated Learning Disability Health Team, where one individual from health is the point of contact; • The Carers Centre; • Child and Mental Health; Educational Psychology Services. • Carers said that good information was available on Education through the ASN Outreach Service (ASD) team. Information on the team and guides are available on the LA website. M/C • Talking Mats (supporting adults and children with a range of communication difficulties) has specialist skills in producing accessible information. SPQ 	<p>syndrome. M</p> <p>Although sources of information exist, 55% of responses to the statutory and provider questionnaire said there was either no clear point of contact or no knowledge of where to get information on services. There is also no clear point of information post school. SAQ</p> <p>Information sources may not be autism specific either. Carers generally described a lack of information and not knowing where to go to get it. CQ/C</p> <p>Some Carers access the internet but not all Carers use this method. C/CQ</p> <p>As well as lack of information there can be overload of information which is equally stressful and difficult to take in particularly immediately after diagnosis. C/CQ</p>
<p>Inclusion/ Acceptance of autism</p>	<p>54% of Carers said the person they cared for was included.</p> <p>"He now has a good friend close by. He regularly goes out for bar meals to his local pub and attends other social events in his local area." A variety of places were</p>	<p>Carers worried greatly about their family members being fully accepted by others in the community. Carers themselves often feel excluded. Not all Carers are able to access school get togethers for parents if they have no child minding support. "You end up being out the loop</p>

	<p>mentioned where people felt accepted and included.</p> <p>Support and understanding from community, neighbours and friends was regarded highly by Carers.</p> <p>Small communities tended to make for better understanding. CQ/C</p> <p>Having good school and college friends was important for people with autism. I</p> <p>The Circle of Friends model helped school pupils to be part of their peer group. CQ</p>	<p>socially yourself even though you don't want to be." CQ</p> <p>There was some worry about the policy to integrate people with learning disabilities into the community when this can be inappropriate to someone who has anxieties in public places if it is not done with thought and care. CQ</p>
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Issues for Consideration

Autism knowledge and awareness

Awareness raising was a big theme for young people who attended the workshops.

- People with autism expressed a real need to raise awareness and to recognise rights. I.
- Individuals and Carers also talked about the need for a national awareness campaign.
- More awareness raising opportunities across the board were required.
- Given that many Health professionals do not have the specialism in autism it was suggested that there is a need for a named trained staff member that can provide awareness raising and support across Health Services. C

- Another area where awareness could be improved was more understanding of gender differences with autism. CQ

Communication & signposting

Carers and professionals both agreed on the need for better information and signposting.

- A specialist hub was seen as the ideal option to provide this type of support. CQ/C/M

Inclusion/Acceptance of autism

Individuals and Carers wanted to see:

- More opportunities for children and young people to socialise in and make friendships in a safe environment; CQ
- More awareness raising with mainstream teachers as part of the Inclusion agenda;
- Mainstream schools influencing other parents and helping change negative attitudes;
- More inclusion in the playground.
- Carers also wanted to see quicker access to social opportunities. CQ

There was a general feeling that more support and understanding was required everywhere. CQ/I/C

There was a role for services to build the capacity of communities to provide support. Having more opportunities to access and be involved in the local community would give people with autism more options for inclusion.

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>There is a strong culture of information sharing, coordination of activities and consultation with each other particularly at the level of the individual practitioner. M</p> <p>There are also a good number of sources of information available to parents and individuals and professionals alike. Information is also produced in large print and other languages.</p> <p>Stirling LA website is a source of information on education and autism. SAQ</p> <p>Getting It Right For Every Child is a shared approach for people who work with children and young people and their families. Shared paperwork is one example of GIRFEC in action. The aim is for everyone to be using the same Forth Valley Integrated Assessment Framework forms to create a single record for the child as they grow up. M</p>	<p>Accessible information on services is an identified gap and while there are elements of information these are not joined up or fully autism focussed. SAQ The result for Carers and people with autism is that while there is voluntary support out there, it is so hard to find out about. SAQ/ SPQ</p> <p>On an individual level parents often have to complete various forms which they feel duplicate information or are vague. CQ</p> <p>The present LA Information system (SWIFT) does not include a specific category for autism. This is an identified gap which the LA believes needs addressing. At present many service users with autism will be categorised under headings such as Mental Health or Learning Disability.</p>
Services - Access/Gaps/performance	<p>The majority of service providers and statutory agencies seek feedback from service users to help</p>	<p>People experienced long waiting lists for services. Only 40% of Carers said the support needs were fully met.</p>

	<p>improve their performance. SAQ/SPQ</p>	<p>There was the recurring theme of understanding. CQ/CW</p> <p>A large gap in provision for people post school was identified. CQ/C/SAQ/ SPQ</p> <p>Some professionals felt parents and young people were being let down with good work going on within the education system for this to fall away when leaving school. While Self Directed Support was an opportunity for families to have more say over care and support, the perception was that the system so far seems very little used. C</p> <p>Carers were very concerned about funding cuts in the current climate and the impact this will have on services. C</p> <p>Social work was highlighted by some as a service which was hard to contact. C</p> <p>Speech and Language Therapy was very good but the availability was thought to be patchy and unknown. M</p>
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Issues for Consideration

Information/Data sharing

- Having a strategic lead for autism would help to address the problems of robust data on autism and information on autism.
- The further development of the SWIFT system will ensure better recording of prevalence in the area which should support accurate service planning in the long term.
- One suggestion from a Carer's group was to have a Stirling Autism Website. C
- An Information Hub would again support an information process for families and people with autism as well as professionals.
- Another was to ensure that the front line workers who are often the first port of call for information such as the health visitor have up to date information and signposting advice.

Services - Access/Gaps/performance

- People experienced long waiting lists for services. Only 40% of Carers said needs were fully met. There was the recurring theme of a lack of understanding. CQ/C
- A large gap in provision for people post school was identified. CQ/M/SAQ/ SPQ
- Some professionals felt parents and young people were being let down with good work going on within the education system for this to fall away when leaving school.
- While Self Directed Support was an opportunity for families to have more say over care and support, the system so far seems very little used. C
- Carers were very concerned about funding cuts in the current climate and the impact this will have on services. C

- Social Work was highlighted as a service which was hard to contact. C
- Speech and Language Therapy was very good but the availability was described by some as patchy and unknown.

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>For children within NHS Forth Valley there is a diagnostic pathway agreed with the three local authorities. M</p> <p>Appointments are made after diagnosis to consider diagnosis with the child and useful perspectives and strategies with parents.</p> <p>There is an autism support group for parents of children recently diagnosed. Getting an early diagnosis can help Carers understand behaviours and can provide further input e.g. Early Years Speech & Language Service and early intervention from the ASN team. One Carer described how the paediatrician and psychologist involved were keen to give diagnosis so more support/services could be accessed. When Carers had a positive experience it tended to be because their situation was straightforward and there was no delay in</p>	<p>81% of Carers who answered questions on diagnosis, experienced problems. The main problem related to a delay before a diagnosis was agreed. Other problems related to the emotional and traumatic impact of the process and where co morbid conditions existed e.g. Down's Syndrome or other developmental delays which added to the complexity of diagnosis. A number of Carers across workshops and questionnaires said there was a lack of information and support post diagnosis.</p> <p>NHS Child and Adolescent Mental Health Service Forth Valley (Falkirk/Stirling) identified that it has the smallest number of professionals per head of population on mainland Scotland.</p>

	getting the diagnosis.	
Interventions (universal) for all services	No comment made	No comment made
Early Intervention approach	The ASN Outreach team has produced a guide to early intervention for early years establishments, schools and professionals. The Staged Intervention process has been identified to meet the needs of children and young people in nursery and schools who need additional support. Information is available on the LA website. The Community Early Assessment Team is an assessment service for children under school age with complex needs run by Forth Valley and Stirling Council. It provides a coordinated approach through a one stop route to assessment and joint working between professionals and parents. Some providers offer intervention programmes. Speur Ghlan provides programmes for children aged between 6 months and 5 years.	Lack of early recognition of autism can result in a lack of early intervention. Some Carers identified the escalation of problems because there was no support in the early years. CQ
Multi-Agency/Partnership/Pathway, Communication and Co-ordination of services	Stirling and Clackmannanshire Council have had shared Education and Social Work Services. There are varying joint funding arrangements: For example: Stirling and Clackmannanshire jointly fund residential provision, service level agreements exist between SLT in both Stirling and Clackmannanshire. Within	As identified, while there is a lot of individual joint work or information and task sharing taking place it can often be ad hoc and not particularly related to a clear pathway of intervention. Discussion in the multi-agency event around the case studies presented suggests a lack of clarity particularly on a pathway around those individuals with autism who have Asperger syndrome or are high functioning adults and not known to services. A pathway

	<p>Education/ SW there is joint funding and planning with Health to provide support to children and young people and families. The Stirling and Clackmannanshire Learning Disability Team is an integrated team involving Health and Social Work. There is also a Health professional forum looking at Autism Pathways. This group is linking to senior colleagues in developing policies and guidance across Forth Valley and looking at joint commissioning of LD inpatient services including complex LD and autism. (SW and Health)</p>	<p>to support for Carers is also not clear. M</p> <p>One service providers said that there were barriers in engaging with some public sector partners not fully recognising and valuing their work. SPQ</p>
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Issues For Consideration

Diagnosis

Carers wanted to see:

- Diagnosis Guides which should be available at the point of need and not be overwhelmed by too much information at once; C
- Front line services having more awareness of autism indicators which could improve delays in diagnosis (particularly if there is no challenging behaviour or learning disability); CQ
- A better review system where there may be doubts about diagnosis;
- Professionals spending more time with the family as part of the diagnosis process;
- More support for the families when children are first diagnosed. CQ

- Better identification of autism at an early age. CQ

Multi-Agency/Partnership/Pathway, Communication and Co-ordination of services

- Consideration could be given to pathways for support for people with Asperger syndrome. Individuals may often function well but come up against difficulties where there is no clear support pathway. Again it was suggested that a Drop in or Hub could support people who would not be "picked up" by statutory agencies.
- Some service providers wanted to see more opportunities for involvement with statutory partners.

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	<p>One Carer described how the school worked well to shape the environment to support the young person by:</p> <ul style="list-style-type: none"> • Putting in place a routine; ensuring there was opportunities for down time; • Providing an adjusted timetable, Giving passes to leave class; • Being removed from certain subjects that 	<p>The popularity of some social activities such as those run by Plus can have a detrimental effect where there is a noisy environment created. This makes it difficult for some individuals to use the service. C</p> <p>Within the school environment problems were identified with breaks and lunchtimes where crowding and noise were sources of anxiety. CQ/I</p> <p>Day services were also cited as being unable to offer the calm peaceful environment required by individuals who</p>

	<p>caused anxiety;</p> <ul style="list-style-type: none"> • Providing a visual timetable; • And clear instructions and routines and using the child's planner. CQ 	<p>experienced noise sensitivity. CQ</p> <p>One Carer identified a problem in obtaining a sensory profile because the OT service did not have trained staff. C</p>
Reasonable adjustments to accommodate autism	<p>A recent example has been the first autism-friendly show in Stirling at the MacRobert Centre where a performance was exclusively for audience members who would benefit from a more relaxed theatre environment, including people with autism took place.</p> <p>Within education other examples were:</p> <p>One to one teaching (secondary school) at times of stress for the child meant the child continued with his education rather than being excluded; CQ</p> <p>Engaging the whole school at assembly including catering, and janitors with specialist input from Scottish Autism helped paved the way for individuals with autism making the transition. CQ</p>	<p>Accessing busy waiting rooms for clinics and GP consultations often proved difficult for Carers CQ.</p>
Service Responsibility including lack of service for people with Asperger's and high functioning autism		<p>Through the cases studies participants attending the multiagency event identified a lack of support for the harder to reach population who do not have a diagnosis. Also while there are services in place for people with autism who have a learning disability these are less</p>

		<p>available for people who have autism and no learning disability as they don't meet eligibility criteria. People with Asperger syndrome are not regarded as a priority for services. M</p> <p>Mental health can go unrecognised too particularly if there is main diagnosis like a learning disability. M</p> <p>Often there is no clear agreement on what Social Work team should be involved with an individual's case. M</p> <p>There is inequality in the Speech and Language provision particularly for more able adults. M</p>
<p>Criminal Justice including Police/ Autism Alert Card</p>	<p>The Autism Alert Card is a partnership between Scottish Autism and Central Scotland. This scheme allows the emergency services to identify, at an early stage, that those carrying the card have an Autism Spectrum Disorder (ASD). The aim is that staff can cater for needs at the earliest opportunity and offer the best support and reassurance. It can be particularly useful if a person who has autism comes into contact with criminal justice professionals, such as police officers, magistrates and solicitors.</p> <p>55% of respondents who answered questions on criminal justice said that the person they cared for had a card. CQ</p>	<p>Only one individual had experience in showing the card. The Carer said that her son had been taken to the police station in handcuffs and the Carer phoned as the named person on the card. No other details were provided as to the effectiveness of the card by the Carer. CQ</p> <p>The card is not widely known about and individuals have to make application for the card. CQ</p> <p>The criminal justice system is given guidelines on how to deal with suspected autism or confirmed diagnosed cases but there was a belief by one Carer that many do not take this into account. CQ</p>

<p>Education/Further Educations – including pre-school/mainstream and autism specific</p>	<p>There were good examples of teachers listening to the child's point of view and opinions across specialist and mainstream provision. CQ/C/I</p> <p>What was working was:</p> <ul style="list-style-type: none"> • Having resources such as small classes; • Home visiting teachers; • Support from specialist early years teacher & speech & language therapist; • Daily diaries; • Good attitudes and understanding which helped young people gain in confidence; • Being able to vary time between the unit and mainstream provided a flexible curriculum as did helping the young person to move on from school by getting employment or accessing the right college placement. 	<p>There was a lack of consistency through all areas of education. When asked about whether primary and secondary education met their child needs, 50% described a negative experience, 25% described a positive experience 25% described said the needs had been partially met. Much was dependent on individuals (heads and class teachers) to make things work but again lack of understanding and using the same approach with all children made for a poorer experience. Some Carers said that the school did their best in the circumstances but resources and knowledge were key issues.</p> <p>Bullying by other pupils, labelling and stereotyping in mainstream education were problematic. A lack of opportunity within mainstream school and an underestimation of ability were described by some young people. I</p> <p>There was a belief that college did not understand autism. C</p>
<p>Employment/ Employability</p>	<p>When young people get work experience opportunities these have been very positive and help evidence the young person's potential. CQ</p> <p>Getting a good job was a big theme for young people who attended workshops. It was an important reason</p>	<p>The multi-agency workshop identified that there was not enough links between supportive employers and school. Carers had concerns that budget cuts may potentially hinder any future prospects of real employment opportunities. CQ</p>

	<p>to do well at school. People had strong aspirations for employment. "Being an actor", "Being an Engineer."</p> <p>The Employability Service Stirling provides specialist employment advice and support for a client base with a range of health conditions including learning disabilities and/or autism. This advice and guidance range from training, vocational profiling, job coaching, liaison with employer and work placements. The team can work with young people age 16 to 17. One individual who had a job said that he had supportive and helpful colleagues.</p>	<p>One Carer said that work placements arranged by the Job Centre didn't work and resulted in a loss of Benefits. CQ</p> <p>One employment professional said that within 16 Plus Activity Agreements, there needs to be for more knowledge of what is available. Many YP with autism need the wider support from more than one agency and there could be more partnership working in these cases.</p>
Housing	<p>Having good supported accommodation with the appropriate level of staffing was valued by Carers. This ensured safety and opportunities to have things to do in the community. CQ</p>	<p>Carers had concerns about the future and this included opportunities to live independently with the availability of the right support to allow this. CQ/C</p>
Respite	<p>Good respite or short breaks help Carers to continue with their caring role. Carers mentioned specific facilities as working well. These were :</p> <ul style="list-style-type: none"> • Nickirian Care, Glenrothes The Bungalow is a small respite service dedicated to providing individually tailored short breaks; • Home-Start Stirling offers informal support by matching families with a suitable volunteer who will visit them in their own home; 	<p>Carers are worried about cuts to much needed respite. One Carer talked about the delay in the annual review for respite. This resulted in a delay in being able to book places. As a result the respite facility was almost fully booked for the year ahead. The Carer went on to highlight a reduction in the respite allocation. (From 46 nights to 21 nights plus 7 emergency nights) which was not enough given the health problems of the adult child and family Carers. CQ</p>

	<ul style="list-style-type: none"> • Crossroads Caring Scotland. A national charity providing home based respite through short breaks/longer periods of support; • Tayvallah Action for Children Scotland Family Support Service. 	
Transport and Rural Issues	<p>Part of Stirling/Clackmannanshire is rural in nature and one advantage identified is that the schools can be more supportive with smaller classes. C</p> <p>ArtLink is supporting greater access to cultural venues through the programme offering programmes on Friday evenings for young people in rural areas where there is isolation. SPQ</p>	<p>There are challenges faced by support services and by Parents and Carers who don't have access to information or services in rural areas. C/CQ</p> <p>Travelling a distance to access appropriate nursery provision was one of the disadvantages that living in a rural area brought with it. CQ. Fewer chances for children to meet up with others was another disadvantage. "Rural areas really have nowhere for help with younger children sometimes they would like to meet others like themselves but have to travel great distances." CQ</p>
Autism Specific Services for Children and Adults	<p>These facilities were seen as conducive to the needs of people with autism, had well trained staff who understood. Carers highlighted:</p> <ul style="list-style-type: none"> • Riverside Primary School; • Primary and Secondary ASN Outreach; St Modan's High School. 	<p>One group of teaching professionals said that while specialist provision within a specialist base attached to mainstream school was very good, there could be an assumption by mainstream education that all of the additional support would be provided by the specialist unit only. This did not always lead to a fully inclusive approach.</p>

	<ul style="list-style-type: none"> • Scottish Autism has a range of day, services for people with autism. This includes New Struan School an independent residential and day school for young people with an Autism Spectrum Disorder (ASD). • Lochies School for primary aged children with complex and additional support needs sharing a site with a mainstream primary. At the present time within Clackmannanshire there are plans for new primary provision for children with autism, and strengthening the Outreach Service available from the Inclusion Team to work with children with autism in schools. 	<p>In the current climate, autism specific services aren't always the cheapest option and commissioners are under pressure to make financial savings.</p> <p>There is fear from specialist providers that budgetary pressure could be to the detriment of autism specific services. SPQ</p>
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Issues For Consideration

Environment including sensory

- Carers also thought there was a real need for specific autism friendly provision. "There should be more recognition of noise sensitivity and daycare buildings should have suitable quiet rooms where adults can retire to when desired. This would help people feel safe and secure." CQ
- Carers wanted to see hospitals and clinics being more autism friendly. Examples such as early appointments could help to make it easier for people to attend without becoming anxious or stressed. CQ

Education

In relation to education, what would help would be:

- Generally better strategies for learning for children on the spectrum and a wider focus within the curriculum not just on academic skills; CQ
- Better liaison with parents; CQ
- More support within schools;
- Improved empathy with parents by head teachers; CQ
- Buddy systems at college and school; CQ
- The further development of the Circle of Friends model;
- More available and appropriate college places.
- Young people also felt learning development reviews did not taking place regularly enough. And wanted to see reviews in school 3 monthly. I
- Better links between supportive employers and school;
- There should be more agencies with specialisms in autism involved in future routes for young people with autism.

Service Responsibility

- More clarity was required on the appropriate social work intervention teams for on-going support post- school: mental health/disability. SAQ

- There is a need to consider how to support those individuals such as people with Asperger syndrome who presently are falling through the gap in provision.

The ACAS project (Access to Community Assessment and Support) is presently carrying out a Needs Analysis. The aim is to recognise the community support needs of this group which will ultimately lead to a more coordinated multi agency approach. CQ

Employment/Employability

With regard to improved employment opportunities:

- Help with future employment was required in the area. I/C/CQ
- More referrals being made to the Employability team; M
- Employer awareness raising; I/C//CQ
- More Supported Employment services. CQ

Housing

A respondent to the questionnaire from housing said that training of housing to help staff spot tenants/ homeless customers group with autism would be welcomed as this would improve the appropriate housing support that could be provided. SAQ

- People with autism wanted their own homes in the future.
- The option for more sheltered housing with additional Carer support needed explored. CQ
- Another issue was safety in the home and advice on how to make the home more appropriate and safe. CQ

Respite

- Carers are worried about cuts to much needed respite.
- One Carer talked about the delay in the annual review for respite. This resulted in a delay in being able to book places.
- As a result the respite facility was almost fully booked for the year ahead. The Carer went on to highlight a reduction in the respite allocation. (From 46 nights to 21 nights plus 7 emergency nights). Which was not enough given the health problems of the adult child and family Carers. CQ

Rural

More help for rural communities in the provision of services and social activities. CQ.

Autism Specific Services

There needs to be a recognition that many individuals will and do require to have access to the specialist interventions through specialist provision as mainstream provision will not always be the most appropriate route. C/CQ

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	<p>Central Advocacy Partners have secured 3 years funding from the Autism Development Fund. This is providing advocacy for young people aged 14 – 25 with an Autism Spectrum diagnosis who live in the Forth Valley area.</p> <p>One Carer described how the Outreach worker provided a good sounding board and advocate for the child at school. This was down to being able to meet with the young person individually and listen to what they had to say. CQ</p>	<p>Carers are often unsure how to navigate the maize of services/ funding and often feel they don't have access to people who could help them speak up. C/M</p>

Issues For Consideration
<p>Advocacy</p> <p>One Carer suggested having support and advocacy services in place when negotiating care.</p> <p>Given the changes to care provision through self-directed support and the tightening of funding streams this was regarded as a particular</p>

need.

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>There were many good examples of support across transitions in education. If there had been a diagnosis there was more chance of additional support. ASN Outreach team were seen as a good resource through transitions in education. C</p> <p>St Modan's school received £14,000 from the Autism Development Fund to develop work experience and life skills projects within the school.</p> <p>Examples of what was working well included:</p> <p>Creative Leavers - a project with Artlink and Education</p> <p>Transition Workers;</p> <p>Support from Early Years to ensure strategies in place to support the child and staff (pre-school); Visits, given the names of other parents, phased entry (into primary); CQ Excellent communication between primary and secondary school working well together</p>	<p>Carers responses suggested a varied experience:</p> <ul style="list-style-type: none"> • Transition into Preschool 36% had a positive experience; • Transition into Primary 63% had a positive experience; • Transition into Secondary 66% had a positive experience. • Transition to Adults services 37% had a positive experience. <p>Comments included</p> <p>“No obvious support to assist transition from school to further education/employment.” CQ</p> <p>“The school planned and prepared my daughter for the change but late involvement of adult social work resulted in late and rushed selection of care provider with little</p>

	<p>and continuity of key primary staff supporting for a period in secondary school; (into secondary).</p>	<p>time for proper handover.”</p> <p>“Lack of consistent transition planning within the local authority.” SAQ</p> <p>Carers worried greatly about the future when they would no longer be able to care. CQ/C</p>
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Issues For Consideration

Transitions

Carers responses suggested a varied experience:

- Transition into Preschool- 36% had a positive experience;
- Transition into Primary - 63% - had a positive experience;
- Transition into Secondary 66% had a positive experience.
- Transition to Adults services 37% had a positive experience.

Comments included from one Carer:

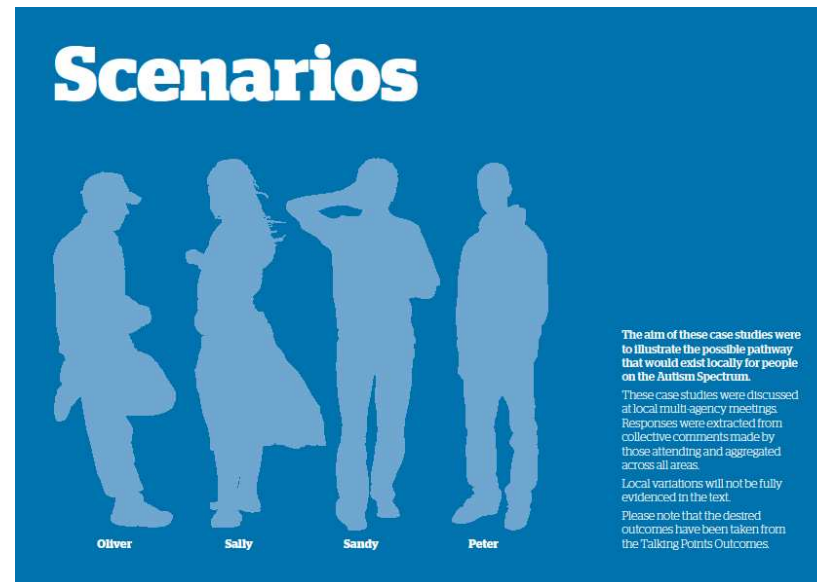
“No obvious support to assist transition from school to further education/employment.” CQ

Consideration should also be given to future planning for older families when carers will not be able to provide the same level of care and support.

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/>

Appendix 1 - Respondents across the Mapping Exercise

Activity	Participants
Multi Agency Workshop	37
Carer Workshop 1 (Stirling)	3
Carer Workshop 2 (Stirling)	14
Carer Workshop 1 (Clacks)	1
Carer Workshop 2 (Clacks)	2
People with autism workshop 1 (Stirling)	9
People with autism workshop 2 (Stirling)	16
Statutory Questionnaire (Stirling)	16
Provider Questionnaire (Stirling)	5
Statutory Questionnaire (Clacks)	0
Provider Questionnaire (Clacks)	5
Carer Questionnaire (Stirling)	28
Carer Responses (Clacks)	12
People with autism Questionnaire (Stirling)	2
People with autism Questionnaire (Clacks)	3
Total	153

Carer Questionnaire Responses:

40 Carers responded to the questionnaires across Clackmannanshire and Stirling. Of these:

37 were parents;

1 was caring for a partner;

1 was a foster carer;

1 was caring for another relative.

Age of the Person Being Cared For:

67.5 % were supporting a child or young person within education. Of these:

12.5% of respondents were caring for a pre-school child;

30% of respondents were caring for a child of primary school age;

25% were caring for a young person of secondary school age;

32.5% were caring for an adult.

The youngest person being cared for was 3 and the oldest person was 51.

80% of individuals being cared for were male and 20% were female.

Age of person being cared for:	Clacks	Stirling	Total
Preschool	1	4	5
Primary	2	10	12
Secondary	1	9	10
Adult	8	5	13
Total	12	28	40
Gender Breakdown of Individuals Being Supported			
Male	8	24	32
Female	4	4	8
Total	12	28	40

Diagnosis

52.5% had a diagnosis of autism;

32.5% had a diagnosis of Asperger syndrome;

7.5% had no formal diagnosis but identified as being on the Autistic Spectrum;

5% were waiting on a diagnosis;

2.5% had atypical autism.

Diagnosis	Clackmannanshire	Stirling	Total
Autism	6	15	21
Asperger syndrome	4	9	13
Waiting for a diagnosis	2		2
No formal diagnosis but identify as being on the Autistic Spectrum	0	3	3
Atypical autism	0	1	1
Total	12	28	40

No full demographics were obtained for the Carers Workshops.

Breakdown of Ages-Young People with autism Workshops

	Number Attending	10-14	15-19	Male	Female
Workshop 1	9	1	8	8	1
Workshop 2	16	8	8	14	2
Total	25	9	16	22	3