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GLOSSARY OF TERMS

CEAT: Community Early Assessment Team

Co-morbidities: Two or more existing conditions that are in addition to an initial diagnosis

Diagnosis: when someone is told what his or her medical condition is

Eligibility: Where a Council or Health Service agrees who can have support from the Council or Health service

Inclusion: Where people are supported to live their lives in the same way as everyone else

NES: NHS National Education Scotland

NICE: National Institute for Clinical Excellence

NHS: National Health Service

OT: Occupational Therapy

Outcome: The difference something makes

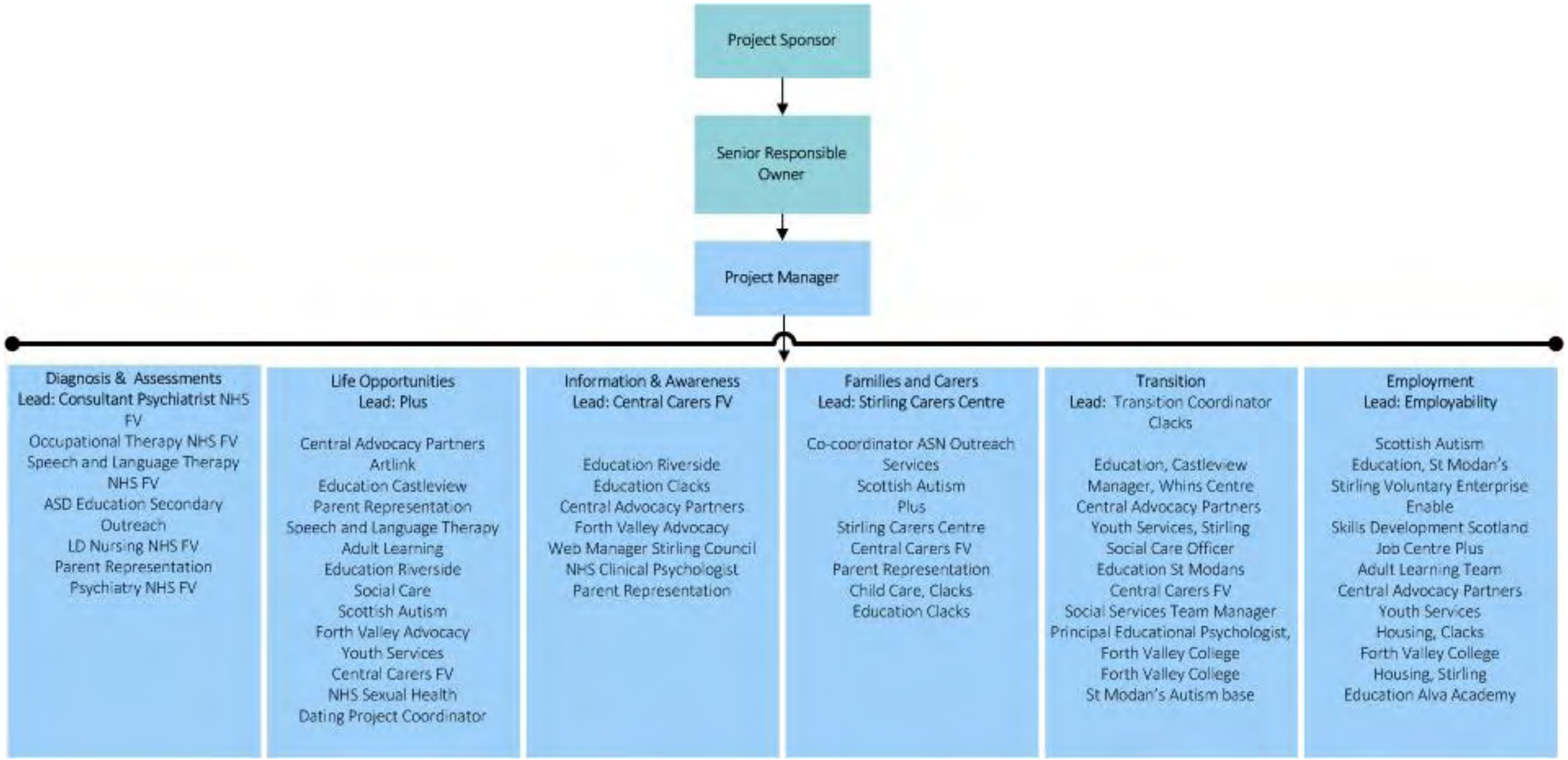
Pathway: A map that sets out what people can expect from services

Personalisation: services are tailored to the needs of the individual

Strategy: A plan that sets out what should be done to make things better

Transition: A process or period of change

STRUCTURE CHART OF PROJECT GOVERNANCE



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Social Care
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Central Advocacy Partners
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ACKNOWLEDGEMENTS

More than 300 individuals have contributed to the preparation and development of this strategy. We would like to thank each and every one of you for your commitment and contribution, in particular those individuals with autism who have shared their stories and experience.

Partners involved with developing this plan are:

- Art Link
- Central Advocacy Partners
- Central Carers Forth Valley
- Clackmannanshire Council
- Forth Valley Advocacy
- Forth Valley College
- Job Centre Plus
- NHS Forth Valley
- Plus
- Scottish Autism
- Stirling Council
- Stirling Carers Centre
- SVE
- Special thanks to Denisa Dashi and Athanasios Faliagkas who have helped develop the Directory of Services for the Autism Forth Valley website

APPENDICES

Appendix 1 – Autism Mapping Report

Appendix 2 – Feedback from Consultations

Appendix 3 – Action Plans

Itsy, Bitsy, Spider, Alex, Riverside Primary School

I Hate It

"I am your fairy dogmother and I would like to tell you a story."
I said "well go on then........."
Once upon a time there was a big lad called Freddie who hated everything.
His friends and his mates got so fed up with him that they wanted to do their own thing.
Freddie went to see Amy.
"Hi Amy, would you like to come out with me?" Do you know what she said? "I don't want to be with you! I don't want to play ! I want to be left alone! "Ok" Said Freddie."I'm just not happy" remarked Amy I'm having a very bad day. Very bad and I hate everything! SO PLEASE GO AWAY!!"
"Ok I'll go away then, I was only asking."
A little while later they met Georgie.
"Hi there Georgie. Would like to play dressing up with me?" "Do you know what she said?" "I'm in a bad mood! I don't want to be with you! I don't want to play ! I want to be left alone! "Ok" said Freddie. "I'm just not happy" remarked Georgie, "I'm having a bad day and I hate everything! SO PLEASE GO AWAY!!" "Ok" said Freddie and thought how rude Georgie was, "goodbye then."
They moved along and a little while later they saw Eddie.
"Hi there Eddie would you like to come to Edinburgh with me?" "Do you know what he said?" "I don't want to be with you. I don't want to play. ! I only want to be left alone." "Ok" Said Freddie. "I'm just not happy I'm having a bad day. Urrrgghh...and
I hate everything so PLEASE GO AWAY!!"
Oh dear, thought Freddie and he felt upset.
"Well well well" said the fairy it's not nice when people are rude and horrid at least you still have a fairy dogmother called Luath to show you everything and what can you do" "Well I am fed up with everyone telling me to go away and I think it's all your fault. I told you I don't like stories and I certainly don't like this one and I wish you would go away too."
Oh there they go.

Freddie White

National Autism Services Mapping Service

Stirling & Clackmannanshire Council Service Map

September 2013

National Autism Services Mapping Project

Stirling and Clackmannanshire Councils Service Map

Contents

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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/Employability		
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 (2001[3]) 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.

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[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 Autism[4] 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, 2013[5]) 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.

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[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 or 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	Young people with Autism attending the workshops described various attributes and indicators of a good quality of life: these were: Trust; Loyalty; Honesty; Respect; Feeling Safe; Consistency; Routine. 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.)	Within the groups young people across all schools identified 3 main issues. Bullying: "Support has been pretty good but little things i.e. bullies aren't dealt with enough." "Other pupils make it hell." "Other people being sarcastic." Communication: "Don't feel able to talk to others with autism especially girls." "Where can I air this point "it's

		hard to bridge the gap " Being stereotyped: "See the label and underestimate." "Can be patronised – feel diminished."
Community and social opportunities	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. Providers also offer social opportunities. Examples were: Plus, providing support to children to have fun and socialise; 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 Scottish Autism has recently set up Kinections 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 Opportunities for social interaction are included in care	100% of Carers said that the person they care for faced social challenges at primary and secondary school (e.g. making and maintaining friendships). 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. Evening and weekend opportunities were also limited through traditional support services. SAQ 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

	plans. SAQ	

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	Service providers described the involvement of people with autism and Carers on advisory boards and steering groups. SPQ The established Autism Action Development Group is seeking the representation of people with autism and family Carers on the group. SAQ	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 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
Carers/Family Support including groups/listening to carers/carers assessment/named person	Most of the respondents to the statutory questionnaire said that they sought feedback from service users and Carers at an individual level. 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: • 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	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 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 "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

	language is appropriate; - 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	

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
- 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	Both statutory and provider agencies offer a range of training opportunities: Within education there is access to local training and funding for autism certificates/diplomas; M Right Click is a web based training programme offered by Scottish Autism; The Richmond Fellowship is providing Scotland wide opportunities for Carers as a result of funding from the Autism Development Fund; Educational psychologists provide a training programme for schools; Speur Ghlan also provides a range of courses and workshops to parents; Carr Gomm's, 'Introduction to Autism Training', is	While there is a lot of individual training there is no full training plan for autism training. M 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

	delivered to all new staff at induction; There are DVDs available produced by young people through PLUS. Providers reported that they worked to person centred approaches at all times. SPQ	
People/professionals who understand	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 The quality of a service was seen to depend on the quality of staff. "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	However not everyone had the same level of understanding. There was criticism of some health professionals such as Dentist/GPs and paediatricians who lacked experience and provided poor input. C/CQ 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

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	38% of statutory and provider responses to the questionnaire said they had a role in raising public awareness. 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. Some older Carers said that there was definite improvement in awareness in comparison to the past. CQ 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	However Carers believed that many professionals didn't understand about autism. C/CQ. This was predominantly within mainstream services with Health and Education being mentioned as particular areas where awareness could be improved. The lack of awareness in the public domain was also raised. C/I/CQ 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 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
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

	information was provided: These were: - 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	syndrome. M 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 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 Some Carers access the internet but not all Carers use this method. C/CQ 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
Inclusion/ Acceptance of autism	54% of Carers said the person they cared for was included. "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	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

	mentioned where people felt accepted and included. Support and understanding from community, neighbours and friends was regarded highly by Carers. Small communities tended to make for better understanding. CQ/C Having good school and college friends was important for people with autism. I The Circle of Friends model helped school pupils to be part of their peer group. CQ	socially yourself even though you don't want to be." CQ 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

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 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	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 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. Stirling LA website is a source of information on education and autism. SAQ 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	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 On an individual level parents often have to complete various forms which they feel duplicate information or are vague. CQ 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.
Services - Access/Gaps/ performance	The majority of service providers and statutory agencies seek feedback from service users to help	People experienced long waiting lists for services. Only 40% of Carers said the support needs were fully met.

	improve their performance. SAQ/SPQ	There was the recurring theme of understanding. CQ/CW A large gap in provision for people post school was identified. CQ/C/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 perception was that 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 by some as a service which was hard to contact. C Speech and Language Therapy was very good but the availability was thought to be patchy and unknown. M

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	For children within NHS Forth Valley there is a diagnostic pathway agreed with the three local authorities. M Appointments are made after diagnosis to consider diagnosis with the child and useful perspectives and strategies with parents. 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	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. 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.

	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

	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)	to support for Carers is also not clear. M One service providers said that there were barriers in engaging with some public sector partners not fully recognising and valuing their work. SPQ

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	One Carer described how the school worked well to shape the environment to support the young person by: • 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	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 Within the school environment problems were identified with breaks and lunchtimes where crowding and noise were sources of anxiety. CQ/I Day services were also cited as being unable to offer the calm peaceful environment required by individuals who

	caused anxiety; - Providing a visual timetable; - And clear instructions and routines and using the child's planner. CQ	experienced noise sensitivity. CQ One Carer identified a problem in obtaining a sensory profile because the OT service did not have trained staff. C
Reasonable adjustments to accommodate autism	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. Within education other examples were: 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 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	Accessing busy waiting rooms for clinics and GP consultations often proved difficult for Carers CQ.
Service Responsibility including lack of service for people with Asperger's and high functioning autism		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

		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 Mental health can go unrecognised too particularly if there is main diagnosis like a learning disability. M Often there is no clear agreement on what Social Work team should be involved with an individual's case. M There is inequality in the Speech and Language provision particularly for more able adults. M
Criminal Justice including Police/ Autism Alert Card	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. 55% of respondents who answered questions on criminal justice said that the person they cared for had a card. CQ	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 The card is not widely known about and individuals have to make application for the card. CQ 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

Education/Further Educations – including pre-school/mainstream and autism specific	There were good examples of teachers listening to the child's point of view and opinions across specialist and mainstream provision. CQ/C/I What was working was: • 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.	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. 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 There was a belief that college did not understand autism. C
Employment/ Employability	When young people get work experience opportunities these have been very positive and help evidence the young person's potential. CQ Getting a good job was a big theme for young people who attended workshops. It was an important reason	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

	to do well at school. People had strong aspirations for employment. "Being an actor", "Being an Engineer." 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.	One Carer said that work placements arranged by the Job Centre didn't work and resulted in a loss of Benefits. CQ 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 me more partnership working in these cases.
Housing	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	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
Respite	Good respite or short breaks help Carers to continue with their caring role. Carers mentioned specific facilities as working well. These were : • 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;	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

	• 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	Part of Stirling/Clackmannanshire is rural in nature and one advantage identified is that the schools can be more supportive with smaller classes. C 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	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 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
Autism Specific Services for Children and Adults	These facilities were seen as conducive to the needs of people with autism, had well trained staff who understood. Carers highlighted: • Riverside Primary School; • Primary and Secondary ASN Outreach; St Modan's High School.	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.

	- 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.	In the current climate, autism specific services aren't always the cheapest option and commissioners are under pressure to make financial savings. There is fear from specialist providers that budgetary pressure could be to the detriment of autism specific services. SPQ

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	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. 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	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

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

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	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 St Modan's school received £14,000 from the Autism Development Fund to develop work experience and life skills projects within the school. Examples of what was working well included: Creative Leavers - a project with Artlink and Education Transition Workers; 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	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 "No obvious support to assist transition from school to further education/employment." CQ "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

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

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:

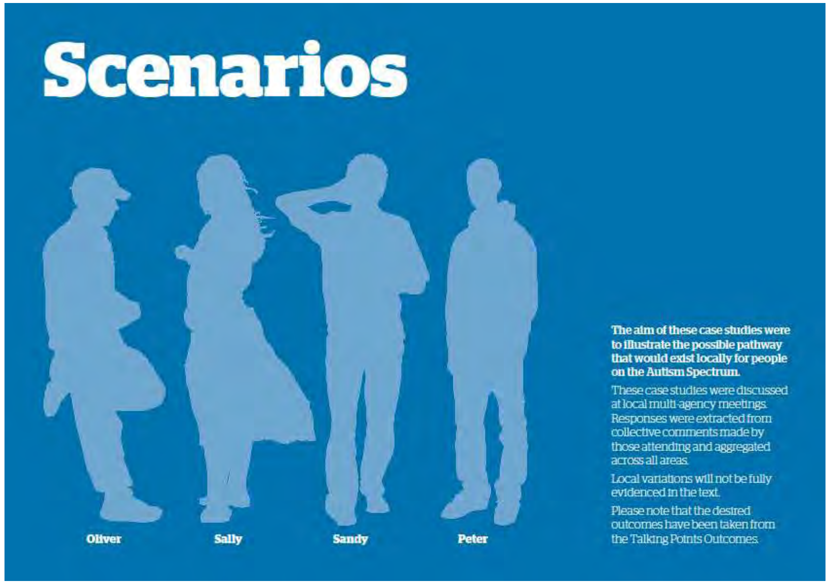
“No obvious support to assist transition from school to further education/employment.” CQ

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.



Scenarios

The aim of these case studies were to illustrate the possible pathway that would exist locally for people on the Autism Spectrum.

These case studies were discussed at local multi-agency meetings. Responses were extracted from collective comments made by those attending and aggregated across all areas.

Local variations will not be fully evidenced in the text.

Please note that the desired outcomes have been taken from the Talking Points Outcomes.

NAS
Scenariosfinal.pdf

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

APPENDIX 2 - CONSULTATION

Methodology

In November and December 2015, the Local Autism Strategy for Stirling and Clackmannanshire conducted a series of consultation events involving approximately 170 service users, families, carers, and professionals, across both local authorities. 101 individuals attended the events organised in Stirling, Callander, Balfron and Alloa and 70 people responded to our online questionnaire (53 in Stirling and 17 in Clackmannanshire).

During these events, a draft of the local Autism Strategy was presented with an outline of the 6 local goals and 16 Key Objectives. A series of round tables discussed more specifically each of these.

What we asked

We asked service users, families, carers and professionals to share their experience and opinions on the services available to people with ASD and we asked whether the local goals and objectives were appropriate to meet the challenges faced by families and people with ASD.

Question 1: asked about the profile of respondents
Question 2 – 9: asked the extent to which people agreed with the goals identified
Question 10 & 11: asked whether the identified goals and priorities address the challenges experienced by people with autism their families and carers
Question 12: allowed for additional comments on the strategy

Responses

The responses we have obtained from the online questionnaires and consultation events are detailed below. Some comments have been edited for the purpose of clarity.

1. Profile of respondents

<u>Online survey</u>
The majority of respondents to the online survey were friends, families and carers of someone with ASD; 54% were carers, 16% were siblings and 3% were a friend of someone with ASD. Eight percent (8%) of respondents were people with ASD. Fourteen percent (14%) of responses were from professionals.

<u>Consultation events</u>
Of the 100 individuals who took part in the consultation events, 65 (65%) were professionals, representing Health, Education, Social Care and a range of Third Sector Organisations.

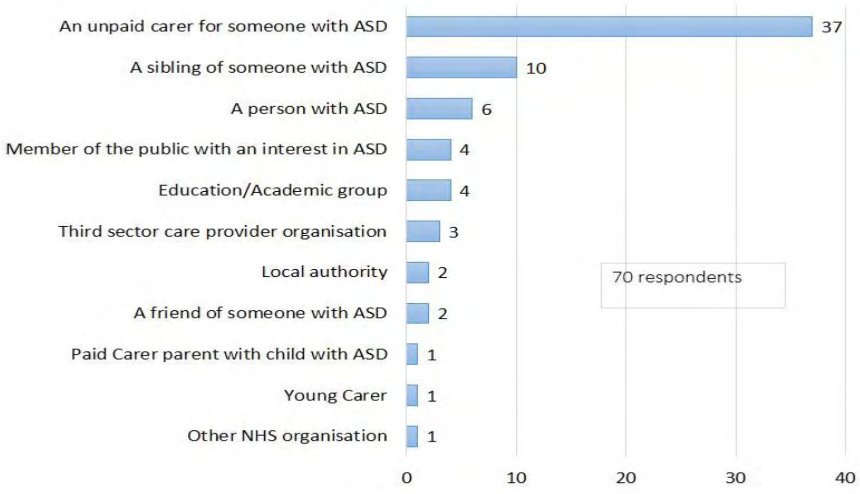


Figure 1: Profile of respondents of the online survey

2. Assessment & Diagnosis

The autism strategy proposes to establish a clear pathway to diagnosis and post diagnosis services for children and adults, with and without a learning disability. The strategy also proposes to be more transparent about the waiting time to access a diagnosis as well as the duration of the diagnosis assessment process.

Eighty three percent (83%) of the respondents strongly agreed with these objectives, a further 13% agreed, and 4% neither agreed not disagreed. The responses received are presented in figure 2.

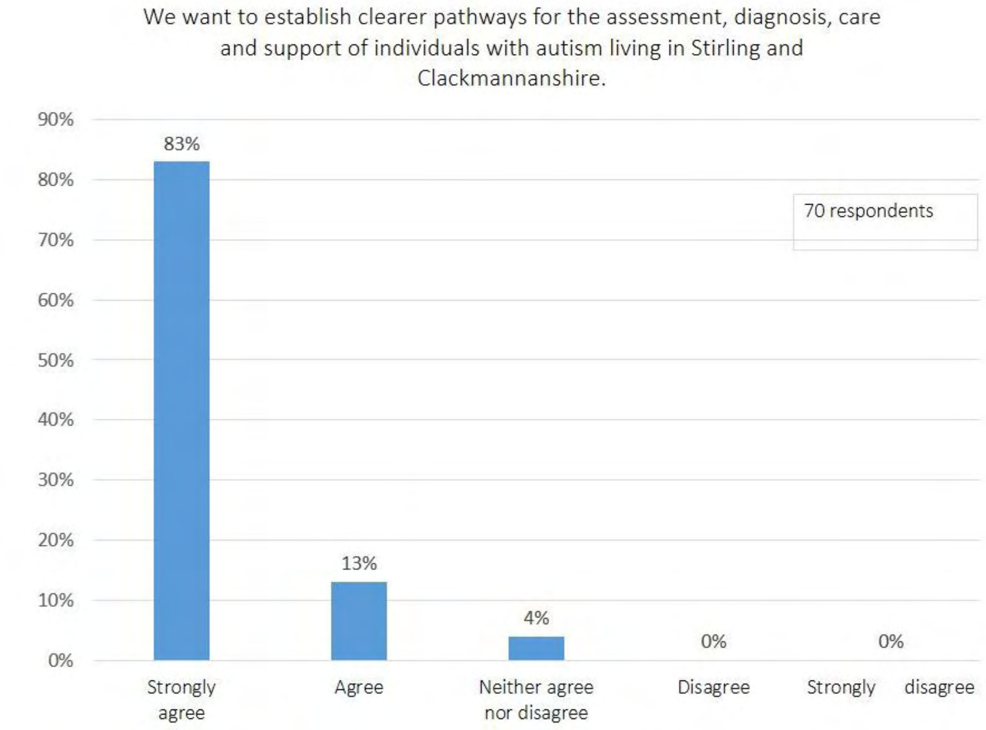


Figure 2: Response to Question 2

The comments collated during the consultation events and from the online survey illustrate the range of problems experienced by families when accessing diagnosis and assessment services:

Difficulties regarding diagnosis and assessment

“Diagnosis for our daughter was initiated by the school, but took 3 years to be completed”

“My daughter is now 16yrs and I’ve been trying to get a diagnosis since she was 4yrs of age, we still don’t have it in writing and she has only been awarded benefits for the last year. We were told she was dyslexic but I have always known it is more, I had to ask my doctor for a referral and CAMHs refused her at first so we had to go back to G.P to re-refer her, so more time wasted, about 6 months. I feel the system has failed my daughter, I strongly agree more support and information is needed as its only through word of mouth and meeting other parents I found out about the referral to CAMHS”.

“The diagnosis of my son took far too long.”

“Very Slow to be diagnosed. No Support after diagnosis.”

“Getting a diagnosis is really difficult, we do not know where to go to get a diagnosis. We spent 6 years in CAMHS without being able to receive a diagnosis, we were then referred to Yorkhill, out with the health board.”

“What happens if CAMHS refuse to look into the diagnosis?”

“Multidisciplinary assessments are bottle necked because a psychiatrist or paediatrician is needed to conclude the assessment and might not be able to do so.”

“What happens for people who are 16-18 and are seeking a diagnosis?”

“A lot of adults get lost in the system”

Lack of clarity regarding the diagnosis pathways

“There is currently no pathway, just a random fight!”

“Links between services are very fragmented”

“I have learnt my own way of dealing with things”

“This (pathways to diagnosis) definitely does not happen currently”

“I believe that the diagnostic process should be more accessible, and that teachers at all levels of education should be given appropriate training to pick up any traits in children that suggest that they might be on the autism spectrum. If these are missed and the child grows up undiagnosed, without appropriate support, they become a very lonely and poorly adjusted adult, often struggling with their everyday life, finding a job, making friends. I am quite certain that such people can get very depressed, and it gets harder as they get older. If they had been diagnosed early in life, all this wasted time could have been used to help them get the life skills they need and help them adapt to living in the society, rather than creating outcasts... “

Insufficient recognition from professionals of the signs of autism across the spectrum of difficulties

“Delayed diagnosis related partly to insufficient recognition of the way autism affects children; e.g. child is naughty and parents are offered parenting skill courses.”

“There is a need for raising awareness amongst a wider range of professionals”

“Is it a speech impediment, or due to his parents having separated, or does he have ADHD?”

“It would help to have teachers who listen.”

“Additional training for CAMHS workers is needed”

“At primary school age: difficulties should be recognised by the schools. Parents often have to wait for the teachers reports to be told their child is experiencing difficulties

Difficulties for adults with ASD without a learning disability to access services

“It (diagnosis) has to be done at an early age as diagnosis in adults is not well supported”

“There appears to be no one to support adults who have Asperger's and don’t have a learning disability.”

Things that would help

“To have an allocated specialist within the community team, especially an SLT (speech and language therapist)”.

“Parents need to have an understanding of why things are happening, what the questions mean”.

“Quick access to services e.g. 18 weeks CEAT (community early assessment team) targets”

“Post diagnosis support for the family, the child or young person and on how ASD affects you and service entitlement”

“Pro-active diagnosis services for children at risk e.g. adopted children”

Things that do not help

“Lack of pathways”

“Come back later, e.g. will not look at this till P1, or come back at P3”

“Waiting for one specialist who is off on long-term sickness”

“Lack of holistic joined-up thinking e.g. it is a speech impediment, or it’s because his parents have separated, or he has ADHD?”

3. Life Opportunities

The autism strategy proposes to ensure that people with ASD feel supported throughout their whole life journey, to live meaningful lives, feel safe, protected, valued and included.

Eighty four percent (84%) of the respondents strongly agreed with these objectives, a further 12% agreed and 3% neither agreed not disagreed. The responses received are presented in figure 3.

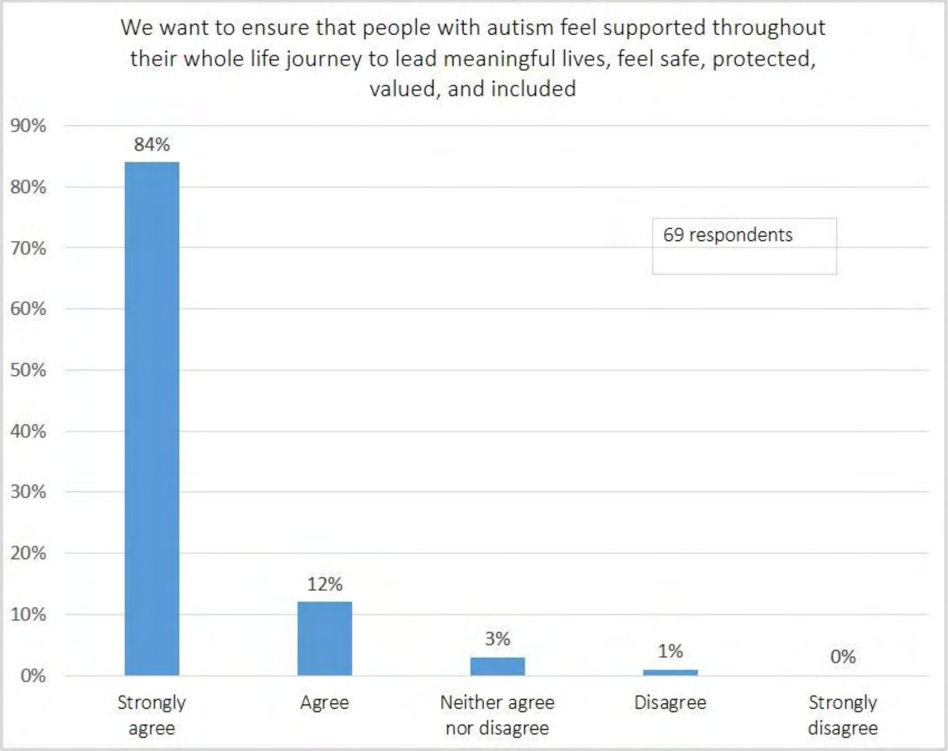


Figure 3: Responses to Question 3

Lack of post-diagnosis signposting

“In Clacks there are few services appropriate for HFA (high functioning autism) ASD (autism spectrum disorder) adults. This group needs to be provided with services and supports”.

“Not much help after diagnosis, unless problems arise”.

“Directories of services for autism would help at post-diagnosis stage”

“Following a diagnosis. families should receive a fact pack”

It was expressed that a range of information on autism, and clarity on how to access local services needs to be available:

“Information for new residents on local autism services is needed”

“How do you access services: pre-school, primary, secondary and post school?”

“Services that deal with each stage? What is there/ what is available?”

“We need information on local contacts, and how to access support groups etc.”

“Ensure events are more flexibly timed for working parents”

“Child care support to enable parents, especially single parents to be more involved”

“Schools are effective at raising awareness if you are lucky”

“We need a one stop shop for all requirements”

“Want information about the benefits one is entitled to”.

“What groups and services are available for “x” age group”

“Fact sheets on ASD are needed”

“List of Autism aware/ trained child care providers needed”

“List of community venues accepting of autism needed”

“Universally available services which people with autism and their families can access as well as specialised services”

“Possibility to develop a scheme to support families with newly diagnosed individuals?”

“List of training offered by autism organisations such as NAS (national autistic society) i.e. parenting”

“Links to Autism tool kits needed”

“Would benefit from including a range of case studies”

“List of places to meet informally/ socially/ feel safe for families of people with ASD (autism spectrum disorder)”

“Greater clarity on the College spaces for autistic users that recognise their needs”

“Would benefit to have safe places for teens/ adults”

<u>Difficulties associated with the geography area as services are centrally provided</u>

“How do we reach people in outlying areas? As this affect access to services, parents cannot afford the cost of transport.”

“Development of support groups in outlying areas?”

4. Supporting Families and Carers

The autism strategy proposes to ensure that families and carers of people with autism are supported and are able to access appropriate services for both themselves and the individuals they care for.

Eighty four percent (84%) of the respondents strongly agreed with these objectives and a further 15% agreed. The responses received are presented in figure 4.

Specific needs expressed by families and carers

“Carers should be supported and empowered to manage their caring role and a life outside caring”

“There are currently budget constraints regarding respite services”

“Access to Plus services are affected, with a restriction on the hours being allocated”

“Parent support groups are helpful and supportive but sometimes it is difficult to meet the needs of all families across the spectrum”

“How do you include the views of parents that cannot attend?”

“Peer support is important: it can be electronic”

“Support plans with input from carers”

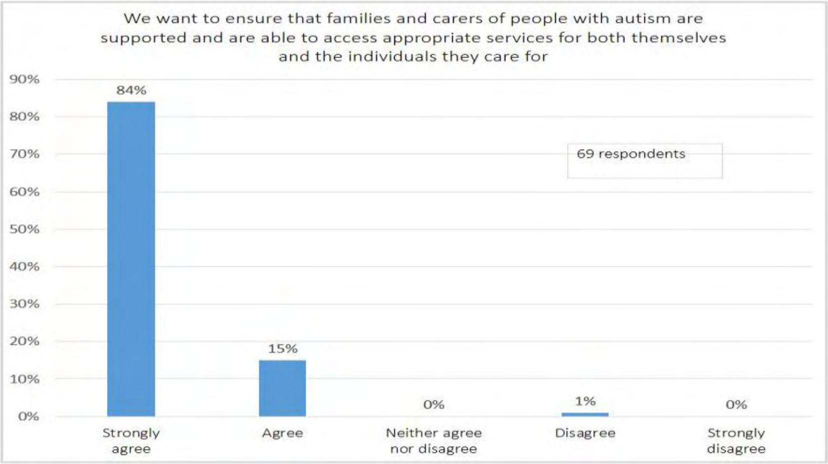


Figure 4: Responses to Question 4

“More respite for the child with ASD”

“Respite for siblings is also needed”

“Choice and variety of respite is important”

“ A holistic carers assessment is more like a conversation than an assessment”

“Carer support in rural areas is needed”

A need for access to a directory of services and better signposting was repetitively expressed

“Better signposting to support families”

“A local service directory is crucial, especially at the diagnosis stage”

“Would like to receive a help information folder.”

“Access to SDS”

“Sibling support: taking away feeling of responsibility”

“Support should be available and accessible locally”

“Consistency of services across areas”

“Information and advice available as soon as possible”

“Build a help folder for parents/ carers pack with all information contained”

“Key role of school in informing of all support options”

"Early planning at every transition stages"

"Access to training and development needed"

"Support should not come down to cost and should fully address needs within resources available"

"Could a telephone helpline be available?"

"What happens to families who need access to support if no diagnosis has been obtained?"

"Would like to have access to social network groups"

"Would like to have access to quality information on Autism and services"

"How do people learn about what is available?"

"SDS: How do we access it?"

"Better signposting to support families"

Issues for carers in relation to physical and mental exhaustion

"If carers cannot cope, the whole thing falls apart"

"Depression: how do parents deal with Autism?"

"Exhaustion"

"Services should be aware of the emotional journey parents go through"

"Problem with loss of income and burden of care"

"Would like a life outside caring"

Inclusion of people with ASD

“How does the community view our children and YP with autism?”

“To make improvement/ change in the community, we need to start with the kids.”

“Inclusion: A safe place scheme to be explored, links needed with the dementia strategy”

“Work is required to ensure this is joined up”

“Physical environment for autism: in parks, links with community council/ lack of fencing in play areas.”

“Parents should be part of the team - communication between families and service providers should be improved.”

“Children in mainstream are educating their parents about aspects of autism”

“Very accepting of children with autism in our schools”

5. Information and Awareness

The autism strategy proposes to provide people with autism, their families and carers and professional's access to clear advice and information.

Eighty three percent (83%) of the respondents strongly agreed with these objectives, a further 16% agreed and 1% neither agreed nor disagreed. The responses received are presented in figure 5.

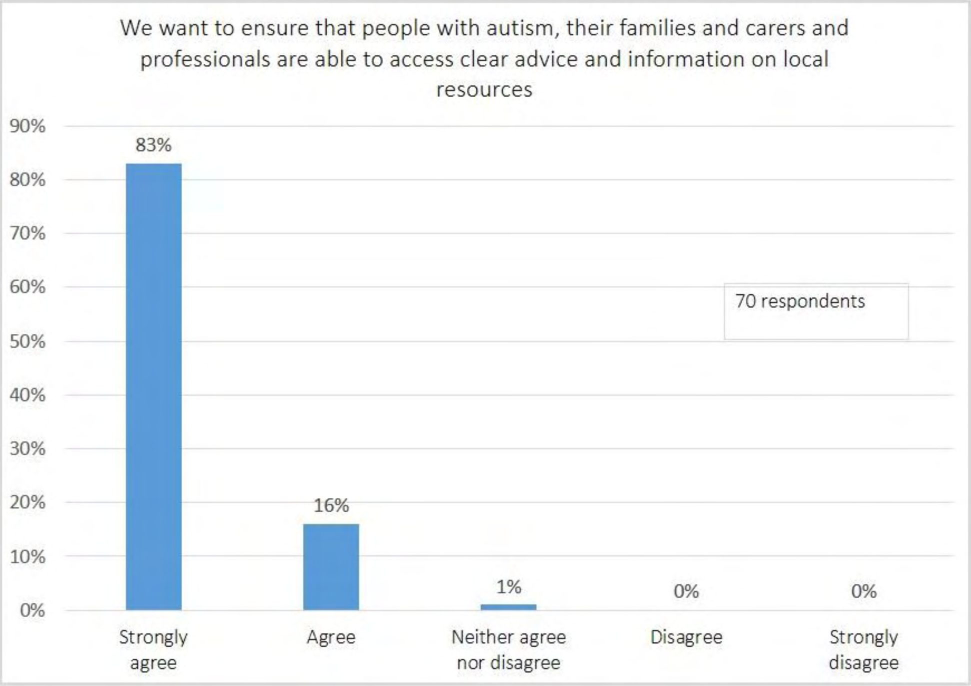


Figure 5: Responses to Question 5

The autism strategy proposes to raise awareness of autism amongst professionals and the general public. Eighty seven percent (87%) of the respondents strongly agreed with these objectives, a further 13% agreed. The responses received are presented in figure 6.

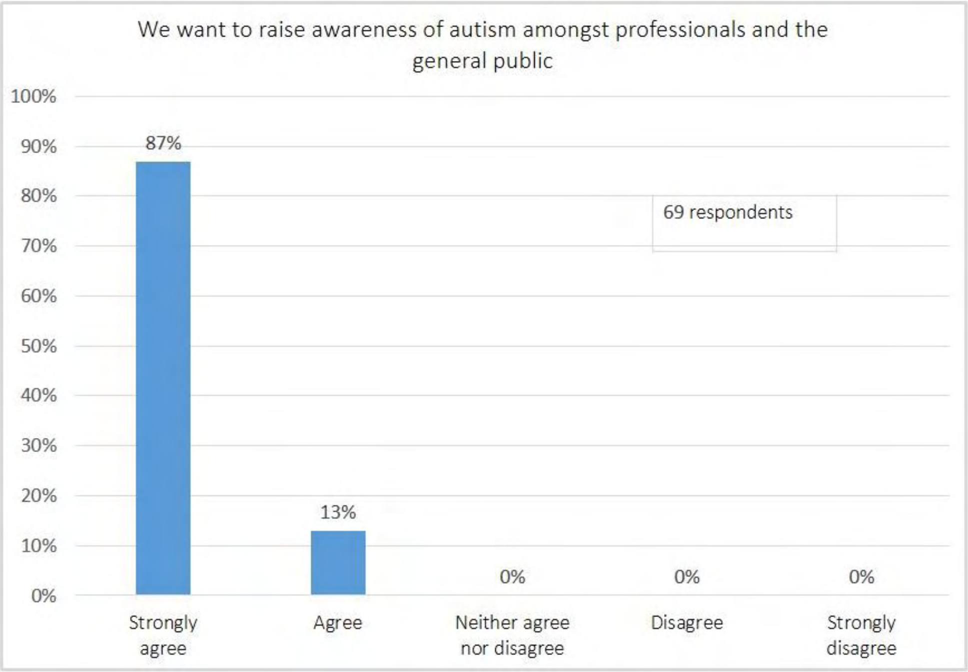


Figure 6: Responses to Question 6

Families, carers and professionals expressed the need to have greater clarity on the services available locally.

“One point of information for all autism services would be great”

“Listing of community venues which are ASD friendly”

“At present quite ad hoc, information at point of diagnosis is variable, lack of information about resources, services, support.”

“Currently after families receive a diagnosis they are sent away without much information on support services available”

“Need to sign post to diagnosis services”

“Could also sign post to experienced parents who are willing to be contacted and offer support”

“Clear information about what next?”

“There is a need to involve all services and agencies to build a menu of interventions”

“Currently it is the luck of the draw if you meet someone who can advise you about what is out there

“Range of options of courses about Autism for parents and professionals?”

“Training available for the whole spectrum not just HFA (high functioning autism)”

“List of events people with autism can attend”

“Support networks - Autism groups”

“Facebook “Pal Stirling” for parents of children with autism”

“Facebook Autism Forth Valley”

Professionals involved with autism could be more informed about Autism

“Schools need to provide support, information on services and be consistent”

“People for Awareness: Hair dressers, opticians, doctors, dieticians”

A need for Autism Training

“There is a growing demand for training”

“Is there the right sort of opportunities for learning for parents with younger children?”

“Online training - would need to be quality assured/ accredited”

“Right click programme from Scottish Autism

“NAS (National Autistic Society) delivered some training last year, but this was one off funding”

“Joint training would be beneficial”

“Courses are fine but first of all, you need someone to hold your hand. You need to be able to talk through things/ peer support from other parents”

“Training should be evaluated”

Request for new services to be developed

“Parent networks are important, good if they are run by parents for parents”

“Autism Champions would be a valuable resource”

“Monitoring for planning purposes needs to be developed across the lifespan”

“Data for adult prevalence is not available”

“Insufficient data in a wider sense”

“Menu of intervention should start with universally available information and then go on to specialist information”

“A website is not enough- services might still not be accessible”

“One stop shop would be a better solution, person to person support, employment, housing, shopping etc.”

“Autistic person to autistic person support and networking”

“Demystification of role of social workers, the support they can offer, it’s not just child protection”

“How can we help those in crisis who need immediate help?”

“How do you ensure sustainability for projects and ideas?”

“Crisis in Puberty - No appropriate placement other than a learning disability ward or England”

“Need a place for 14 + YP with autism to meet up informally”

A standalone autism website for the whole of Forth Valley is needed

“Website should signpost clubs and other mainstream opportunities”

“A website would be great.”

“ Should include opportunities for social interaction”

“Links to other sites/ services”

“List of Services that are autism friendly (i.e. solicitors, hairdresser, shops and cafes)”

“I have other children at home, leaflets with contact numbers are not adequate”

“Good to have resources in local areas”

“Autism Trip Adviser (ratings)”

“What next after diagnosis, what now?”

“It would be really good to have a central point of access for information”

“Issue, how do we judge the quality of information?”

“Places to go for people of all ages”

“Would prefer not too many menus on the website”

“Access to a forum for parents and others to check information”

“Forum to vent anonymously”

“Who will maintain the website?”

“Better clarity as to which service helps with specific problems”

6. Transitions

The autism strategy proposes to improve transitions for children and adults with autism throughout the whole life journey.

Eighty four (84%) of the respondents strongly agreed with these objectives, a further 15% agreed and 1% neither agreed nor disagreed. The responses received are presented in figure 7.

“Too late with information regarding what is happening next”

“College course transition needs to be more effective”

“Need more information about college courses available that can accommodate ASD students more effectively”

“Schools are a very nurturing environment and youngsters are transitioning to a less supportive environment”

“Social work involvement not happening early enough”

“Lack of signposting for parents to identify options”

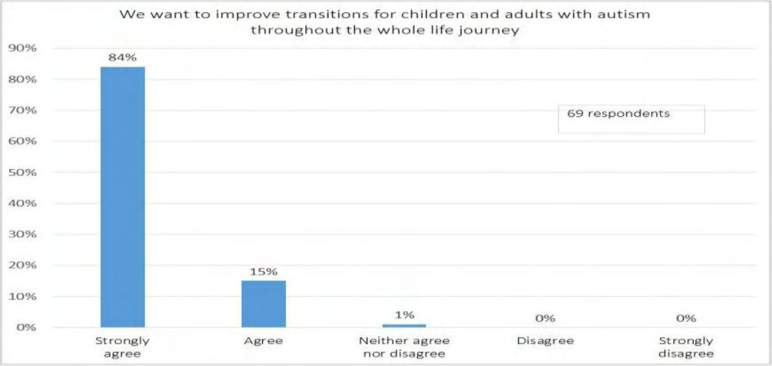


Figure 7: Responses to Question 7

”Transition needs to be better planned”

“Continued need for awareness raising across primary, secondary and post school provisions”

“Poor transition from primary to high school as there is a lack of understanding of Asperger in schools”

“Passport: depends on the receiving service reading the information”

“Lack of continuity between high school and post school services”

“Need for key workers/ coordinator for each young person”

“Parents are having to drive transition planning”

“Appropriate planning transition is required”

“Issues of liaison between families and colleges, what are the students doing? There is insufficient feedback.”

“Insufficient opportunities for continued learning”

“Courses are relevant to the skills and aspirations of YP (young people)”

“Personal learning plan should be shared between school, home or residence”

“Parents are the experts on YP and their autism”

“People moving to a different area?”

“Lack of consistency: e.g. number of different support assistants”

“People with ASD (autism spectrum disorder) need routine and find it difficult to adapt”

“Parents want to be clear about transition pathways”

What are the issues that affect transition?

“How does someone with ASD communicate their needs?”

“How do you monitor transition?”

“There is a lack of signposting and involvement from social services”

“How will a moving on passport be maintained?”

“How is information updated?: Life journey: things do change/ Add and Remove”

“A life plan?: Allocation and reallocation of budget”

“What is happening when a new person with ASD moves to our local area? And vice versa if a person moves to another place?”

“Transition is a daily occurrence”

“School to adult services is particularly problematic”

“Post 18, who will fund place/support at the next stage?”

“Currently, finding out useful information by happy accident”

“When a professional moves on, what is in place?”

“There is a need to build on what has been learnt about the child/ YP (young person) in the assessment process as they move towards adult services/social services”

“There are so many other things you need to do first before moving to a life-long service”

“17 years old, non-verbal and severely autistic/no transition worker identified”

“More regular meetings for young autistic people”

“Parents and carers need to receive some consistency”

An Autism Transition App

“Living document App, basic information available, no repetition, access to appropriate services/ signposting”

“Don’t like the Moving on Passport, an App for specific needs would be better”

7. Employability

The autism strategy proposes to support people with autism to develop skills, which will enable them to contribute to their community through voluntary work or employment.

Sixty eight (68%) of the respondents strongly agreed with these objectives, 28% agreed, 1% neither agreed nor disagreed and 3% disagreed. The responses received are presented in figure 8.

“In the work place there are anxiety issues, employers should be supported/ placement should be reviewed”

“My son is desperate to work and is always thinking of ways to make money. He wants to work in IT (information technology) but the only thing that keeps us back is lack of transport”

“Finding suitable employment for a person with autism without any additional support is nearly impossible“

“What courses are proposed? Who will provide them? Will staff be adequately trained? Research into best practice elsewhere needs to take place, including England and Wales.”

“It may be particularly helpful to provide mentoring (perhaps on an intermittent but long-term basis) and to offer support within the workplace so as to facilitate greater understanding, tolerance of difference and acceptance of individual preferences and styles of communication without prejudice. This would be far more appropriate than to risk "training" autistic people in an old-fashioned / unenlightened fashion, which may only add to their experience of stress.”

“Support services should not end just because an individual reaches an age based milestone. Coordination needs to take place to ensure smooth transition without there being gaps where there is no service provision or support funding.”

“We were fortunate to set up two work placements for our daughter when at high school that have transitioned and continued into her adult life. These are now supported by Employability and over time both placements have extended to a 1/2 day each which is about the level appropriate for her to manage. Recognition of our daughter’s ability and skills are equally recognised by both companies and both appear committed to the future and are currently looking at permitted earnings. This is fantastic and our hopes and aspirations are that she may aspire to full time employment opportunities when she is ready. Our daughter has thrived in this environment and has grown in self-confidence, she is aware of her achievement and has developed skills and social etiquette etc. In addition this has helped raise awareness in the work place and break down barrier and preconceptions of the wider community etc. However, my understanding is that the role of Employability is changing and they will no longer be tasked to source opportunities such as our daughters and this will be a huge loss for others. Our daughter is a wonderful example of how someone with complex and challenging needs, if supported appropriately can develop and contribute as a valued member of society and not be a burden on the state to develop. But support needs to continue after they leave school. Delayed development is prevalent within ASD so why does all the specialist support stop when they leave education? Our daughter was only opening up to learning at aged 15 but it closed down at 18. Perhaps if education was extended as is practiced within the NAS (national autistic society) schools to 21 years, many of our young people would be better prepared and ready for the adult world.”

“At the moment it is very difficult to access employment opportunities for young adults with autism”

“I have had to find volunteer work and work experience for my daughter as part of her school work. The school did not do anything and it took me a long time to find a placement that would accept her with her condition, due to not having insurance cover She could only go to riding for disabled for her volunteer work but they closed down so I applied to Dogs Trust and the school took her, but it was me who organised it all..”

“Ongoing inclusion is essential, but must be appropriate and meaningful to the individual.”

“However there are some adults with autism that may be too affected to do these things. What will happen to them?”

“My experience with my daughter has been horrendous regarding young adults to develop skills”

“I work for Stirlingshire Voluntary Enterprise and recognise the skills people with autism can bring to communities through volunteering. I hope through this work that more people will recognise a person with autism skills and not just their barriers. Which ultimately may mean the community will see them as an equal participant and welcome them into the workplace.”

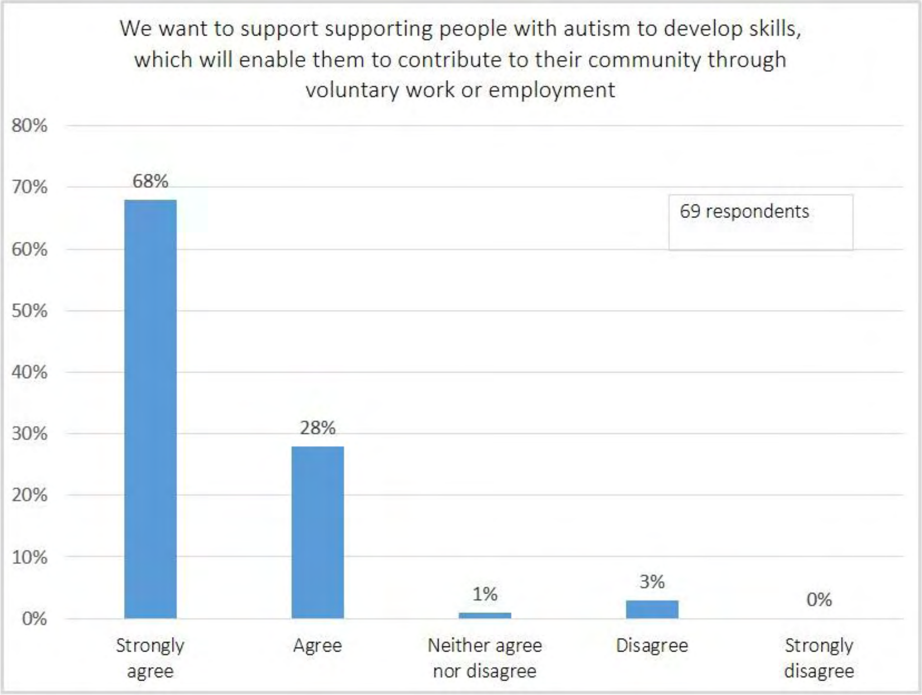


Figure 8: Response to Question 8

8- Are the strategy goals addressing the challenges experienced by people with ASD

We asked whether the goals set out in the draft autism strategy addressed the challenges experienced by people with autism and their families locally. Thirty five percent (35%) strongly agreed with this, 43% agreed, 16% neither agreed nor disagreed, 5% disagreed and 2% strongly disagreed. The results are presented in figure 9.

The comments received for this questions are the following:

“Although I do not have a detailed knowledge of the challenges experienced by people with autism, and their families living in the area, I agree with the 6 local goals as set out in the Strategy document”

“The goals address the challenges experienced by children and families, younger people and for those in transition from Children's services to adult services. For older adults I am less confident that the goals will make much difference”

“Certainly the goals are worth aspiring too. Putting them into practice is the challenge”

“Yes. And I think it’s overdue as I’ve said I really struggled for years, I had not one to turn to or get support from and I’m still not getting any. As you can imagine I’m angry with the system and I can only hope that this makes a difference”

“I think environment should also be addressed, in the same way that Stirling is becoming a Dementia Friendly City, I also feel that it should become an Autistic Friendly City and this should be reflected in shops, parks, entertainment facilities, transportation etc.”

“Objectives mean well but it is the action you take that will make the difference! I have had to fight the local authority every step of the way to get the support my child should be entitled to. GIRFEC, Child at the Centre, and inclusion are great polices in theory but your practitioners and supporting professionals need to learn to put theory into practice”

“Provided that sufficient funding for training and resources is given”

“Help at all levels of schooling, our primary is not as good with children with autism. McLaren High however are excellent with my son, his year head is constantly checking up on him to make sure he is okay”

“Being in an isolated rural area means that there are additional pressures. For example, I have to pay travel for support workers which is very expensive. It costs me £18.90 for each support session”

“I think the most important areas are already covered in the strategy and if these are put in place properly it will make a huge difference to all concerned”

“Social isolation for adults with non-learning difficulties needs to be further investigated and addressed to ensure this group is fairly represented”

“I work in Education and have only read the Draft Strategy. However I didn't see education mentioned very often. Children are within an education environment for at least 13 years and to get it right there has to be the support there. I feel very strongly about this, having Special needs schools or inclusion within a mainstream school takes a lot of adult support. Is this being addressed seriously? Where is the money coming from?”

“Opportunities and resources to enable people to be active, opportunities in local communities are very limited and more so as adults. The impact on individuals mental health needs to be better recognised and supported”

“Yes. I live in Killin and there is no support in the primary school”

“Rural locations suffer. It is a postcode lottery, we see that the inner city receives most resources but we in a rural location have nothing, no support services. The base at Callander for the whole of the McLaren cluster, really! You have a small number of professionals with huge case loads. You need to expand ASN (additional support needs) services which costs money”

“They should have an overview of budgetary considerations for the overall service”

“Funding for appropriate adaptations for houses/ gardens to ensure safety?”

“The strategy should look at how parents can provide young people with ASD (autism spectrum disorder) with appropriate education on those days when they cannot be in school as a consequence of their particular disability. The strategy should also include reference to Self-Directed Support funding and the process for applying for assistance”

“There needs to be more support for children with ASD (autism spectrum disorder)in mainstream schools”

“Siblings need space and time to be away from a child with ASD and siblings need help to understand ASD (autism spectrum disorder) especially if they are younger”

“The main issue for me is being able to access local support and information - I have always found this difficult to find and access.

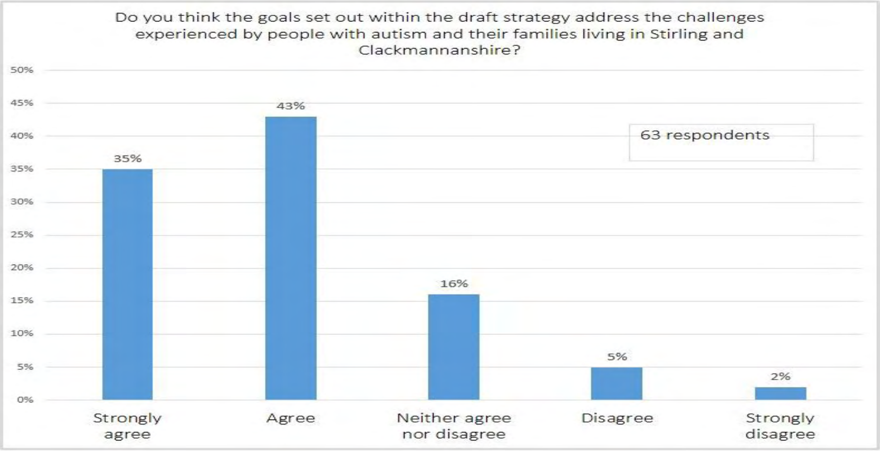


Figure 9: Response to Question 9

9 Are the strategy objectives appropriate to meet the local goals?

Finally, we asked whether the objectives set out in the draft autism strategy are appropriate to meet the local goals.

Twenty two percent (22%) strongly agreed with this, 49% agreed, 21% neither agreed nor disagreed, 6% disagreed and 2% strongly disagreed. The results are presented in figure 10.

The comments we received to this question are included below:

“I took part in the mapping exercise last year and the recent Stirling consultation event, on both occasions I was the only parent of an adult present. I am concerned that carers of ASD (autism spectrum disorder) adults and ASD adults are not being made aware of this consultation, it was only by chance I found out about it. I also received no feedback from the previous consultation”

“My daughter’s school is in desperate need of support. They are stretched thin, the ratio of staff to children is ridiculous, and they have a high number of children with Additional Support Needs. Place your resources into early years and primary provision. The earlier the intervention, the better chance that child has of learning to live with autism”

“An essential piece of work - in which parents must have a significant contribution”

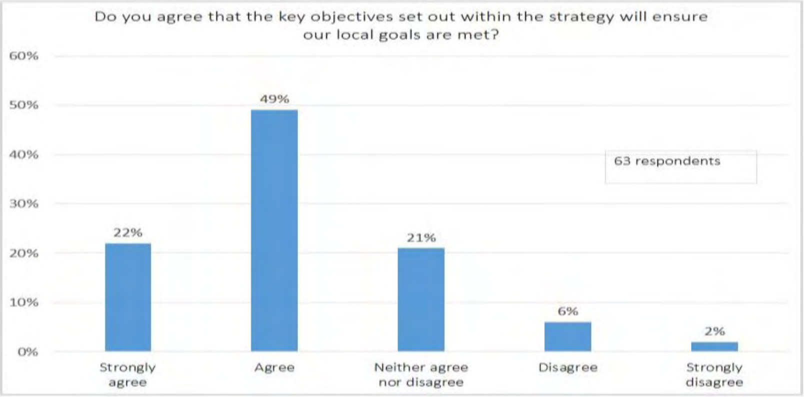


Figure 10: Response to Question 10

SUMMARY

The questions asked were reflective of local issues, gaps in services and a range of concerns raised by stakeholders. We further asked whether the identified priorities would meet the strategy objectives. The majority of responses received confirmed that the strategy goals and priorities are appropriate.

It is apparent from the comments received that families and individuals have experienced a number of challenges, confusion regarding pathways to access services and a lack of information about services available locally. Feedback highlighted individual’s poor experience of assessment and diagnosis services, transition, and employability. Concerns have also been expressed regarding the vulnerability and isolation of families as a result of their caring role.

There were also positive experiences reported which we can learn from. These opinions have been noted and have informed the local strategy.

Workstream 1 : Assessment & Diagnosis

Area for action	ID No	Action required	Responsibility	2, 5 or 10 years	Best Practice Indicators	Outcome
1- Pre-diagnosis						
	1.1	Ensure that GP's, nurses and health visitors are trained in recognising signs of autism and are aware of existing diagnosis pathways	NHS, NES	2 years	2,3,4,8	Improved awareness of autism indicators for those in front line services
2- Assessment & Diagnosis						
	2.1	Multi-disciplinary assessment diagnostic team of health professionals, for adults with or without a learning disability. Essential members to include psychiatry, nursing, psychology, speech therapy and occupational therapy	NHS	2 years	6,8,10	Multi-disciplinary diagnosis pathways for children and adults
	2.2	Evaluate current gaps in diagnosis for adults with ASD, with or without a mental health or learning disability diagnosis	NHS	2 years	5,6,8,9,10	Gap analysis ensuring that significant gaps are resolved.
	2.3		CAMS	2 years	5,6,8,9,10	

		Evaluate current care pathways for assessment and diagnostic procedures within child services and learning disability services and use this to inform a care pathway for adult services	Paediatrics LD			Clear care pathway for adults
3- Assessment: co-morbid health issues						
	3.1	Ensure health staff have appropriate training to recognise and identify problems of co-existing mental health and/or physical conditions and can provide the required clinical support	NES	2 years	2,3,4	All health staff will be trained appropriately
	3.2	Develop training for health staff and other professionals to raise awareness on how unmet health issues can impact on behaviour	NES	5 years	2,3,4	Training available for assessment and intervention.
4- Post-diagnosis: liaise with support services						
	4.1	Liaise with post- diagnosis support & intervention services	NHS	2 years	8	Seamless transfer to post diagnosis services

Workstream 2: Life Opportunities

Area for action	ID	Action required	Responsibility	2, 5 or 10 years	Best Practice Indicators	Outcome
	1.1	Create a directory of local services	All workstreams	2 years	3,6	Clarity on local services for people with autism, families and carers
	2.1	Develop a Menu of Intervention	Education	2 years	2,4,5,8,9,10	Clarity on who can help and sign post the ASD child
	3.1	Produce a parents/ carers' guide to ASD	Education	2 years	2,3,6	Clarity on transitions ahead
	4.1	Create a directory of welfare benefits available to individuals with ASD, their families and carers	Education	2 years	3,6	Clarity on individual educational goals
	5.1	Identify key legislation to support individuals with ASD	NHS	2 years	2,6	Access to services

	6.1	Access to further education/ adult classes	Third Sector Providers, Social Services	2 years	2,4,6	Continued learning
	7.1	Review the availability of appropriate housing options and housing support	Housing	2 year	1,8	Support independent living

Workstream 3: Information and Awareness

	ID	Action required	Responsibility	2, 5 or 10 years	Best Practice Indicators	Outcome
1- Training						
	1.1	Access to integrated training plan for the following: (1) Education (2) Health (3) Care providers (4) Police (5) Front line staff (6) Parents	All workstreams	2 years	2,4,9	An Integrated training plan that delivers appropriate training
	1.2	Training for front line staff in communication strategies, behavioural intervention and IT technologies (assisted communication etc.)	NES, Education, Multi-Agencies, Social Services	5 years	2,4,6	Delivery of better outcomes for people with ASD
	1.3	Define the quality standards for ASD awareness training services.	All workstreams	2 years	8,10	Quality indicators for commissioning ASD services.
2- Information	2.1	Create an Autism Forth Valley website & social networking sites	Social Services	2 years	3,5,8	Good quality, up to date and easily accessible information
	2.2	All partnership organisations to review autism information on their portals	All workstreams	2 years	3,8	Good quality up to date information

3- Awareness	3.1	Autism Awareness Day Sub-committee to plan 6 months ahead for April 15 and April 16	Third Sector Providers, Social Services	2 years	1,3	Increased awareness of autism
	3.2	Develop a Forth Valley “We are Autism Aware” certification scheme for local businesses	Social Services	2 years	1,4	Improved autism awareness in communities
	3.3	Develop a Safe Place Scheme in partnership with statutory and third sector providers, mental health and Learning Disability	NHS, Police Forces, Social Services	10 years	1,4	A safe place for people with ASD
	3.4	Police, Health and Council to identify autism champions to raise awareness of ASD within statutory services	NHS, Police Forces, Education, Housing, Social Services, Criminal Justice	2 years	2,8	Improved autism awareness in communities

Workstream 4: Families & Carers

Area for action	ID	Action required	Responsibility	2, 5 or 10 years	Best Practice Indicators	Outcome
1- Engagement						
	1.1	Families and carers will be more involved in the development of, and have direct input into, care plans	All Workstreams	2 years	1,8	Care plans developed in co-operation with service users, families and carers
	1.2	Families/carers to have access to a support pathway	Stirling & Clackmannanshire Council's (website to be updated accordingly)	2 years	1,7,8	Improved signposting to supports and services for families and carers of people with autism
	1.3	Families and carers will be consulted with on a regular basis with regards to the support offered to the person they care for	All Workstreams	2 years	1,3	Families and carers will be treated as equal partners in care

2-Information						
	2.1	Develop a local service directory for families, carers, professionals and provider organisations	All Workstreams	2 years	3,8	Families, carers and other stakeholders will be well informed on availability of local services and support
	2.2	Promote advocacy services for families and carers	Central Advocacy Partners and Forth Valley Advocacy	2 years	3,7,8	Carers and families will have access to advocacy as required
	2.3	Ensure unpaid carers have access to a Carers Assessment/Support Plan and timely support	Carers Centres, Social Services	2 years	2,4,5	Carers will feel supported to manage their caring role
3- Transitions						

	3.1	Ensure families and carers are informed and supported at each transition stage	All Workstreams	2 years	1,6,8,9	Families and carers are treated as equal partners in care
	3.2	Individual Education Plans (IEP) & Child's Plans for children with autism reflect the views of families, carers and the whole Team Around the Child (TAC)	Education	2 years	5,6,9	People with autism have access to appropriate education provision and consistent levels of support
4- Respite/Short Breaks						
	4.1	Ensure variety and choice of local short breaks that meet the needs of the individual, family and carers	All Workstreams	2 years	7,8,9	Carers report positive morale, emotional and mental health
	4.2	Carers for people with autism will be able to access local peer support	All Workstreams	2 years	1,8	Families and carers are supported to manage their caring role.

	4.3	Evaluate respite/short break options in consultation with service users their family and carers	All Workstreams	2 years	5,7,10	Respite provision meets carers' needs
5. Social Opportunities						
	5.1	Provide appropriate support, information and advice for siblings and young carers of people with autism	All Workstreams	2 years	3,4	Siblings and young carers are supported within their caring role
	5.2	Knowledge of Self Directed Support options	All Workstreams	2 years	6,8	Carers have access to personalised and tailored support
	5.4	Appropriate support should be available to parent/carers who have a diagnosis of autism	All Workstreams	2 years	8,9	Carers with additional support needs receive appropriate support

Workstream 5: Transitions

Area for action	ID	Action required	Responsibility	2, 5 or 10 years	Best Practice Indicators	Outcome
1- Transition Planning						
	1.1	Develop a transition passport Autism App	Education, Social Services	2 years	3,6,8	Improved experience of transition for people with ASD
	1.2	Develop Autism transition planning guidelines for all services	Education, Social Services	2 years	3,6,8,9,10	Improved experience of transition for people with ASD
	1.3	Ensure information on transition and support is available to people with ASD, families and carers	Education, Social Services	2 years	2,3,9	People with ASD, families and carers are prepared for transition and supported throughout
	1.4	Ensure involvement of multi-agency partners in transition processes	Education, Social Services	2 years	3,6,8,10	Multi-agency care pathways to improve the support

						for people with ASD
2- Post School Transition Pathways and destinations	2	Liaise with local services for adults with ASD	Education, Social Services	2 years	4,5,6	Improved access to Life Opportunities, better outcomes for people with autism, crisis prevention
	2.1	Liaise with further education services	Education, Social Services	5 years	4,5,6	Identify and develop employability potential
	2.2	Liaise with employment and volunteering services	Education, Social Services	5 years	4,5,6	Remove barriers to accessing services by aligning eligibility criteria to social, communication and behavioural needs

	2.3	Develop local transition support networks (including support groups, peer support, online presence) to ensure that families are supported through transitions processes	Education, Social Services	2 years	4,5,6,10	Improve access to support services during key transition stages
		Ensure support is available to people with ASD, families and carers during transition	Education, Social Services	2 years	3,6,9	Appropriate and timely support to people with ASD

Workstream 6: Employment Opportunities

Area for action	ID No	Action required	Responsibility	2, 5 or 10 years	Best Practice Indicators	Outcome
Employment and volunteering opportunities						
	1	Review information available to support people with ASD to access employment	Employability, Job Centre Plus, Social Services	2 years	3,6	People with autism will have access to clear information on pathways to employment
	2	Create a directory of Autism-friendly employers	Multi-Agency	5 years	6,8	Individuals with ASD will have positive employment experiences
	3	Review training and further education opportunities available to people with ASD	Education, Social Services	5 years	4,6,8	People with ASD have access to training that will lead to employment and volunteering opportunities
	4	Support Job Centre Plus to develop clear pathways for signposting people with ASD to appropriate services	Job Centre Plus, Social Services	2 years	2,6,8,9	People with ASD are better

						supported into work
	5	Review & evaluate work experience opportunities	Employability	2 years	5,10	Better informed service delivery
		Extend the Job Centre Plus buddy/coach system to include people with ASD	Job Centre Plus, Social Services	2 years	2,6,8,9	People with ASD are better supported into work