Feedback from 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

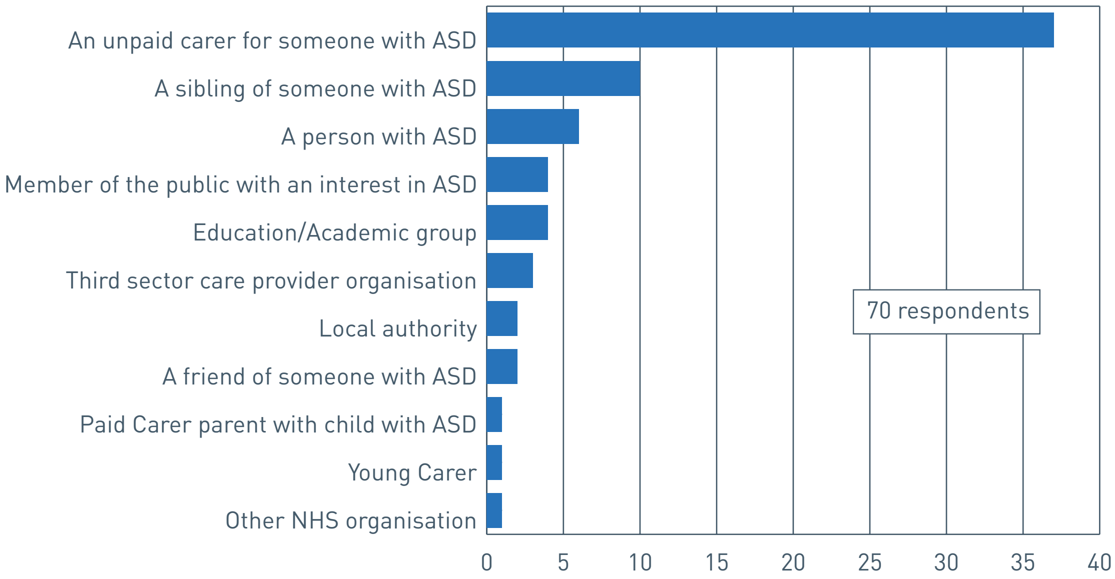
Online survey

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.

Consultation events

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

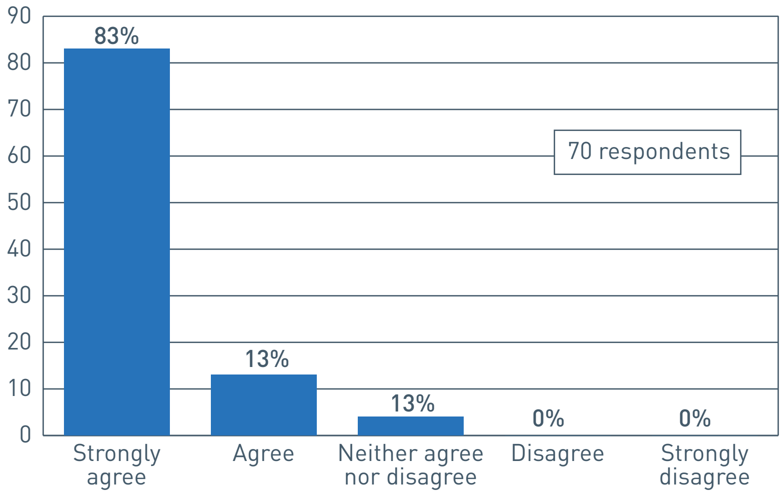
The autism strategy proposes to establish a clear pathway to diagnosis and post diagnosis services for children and adults, with and without a learning disability. The strategy also proposes to be more transparent about the waiting time to access a diagnosis as well as the duration of the diagnosis assessment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

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:

Figure 2: Response to Question 2

We want to establish clearer pathways for the assessment, diagnosis, care and support of individuals with autism living in Stirling and Clackmannanshire



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?"

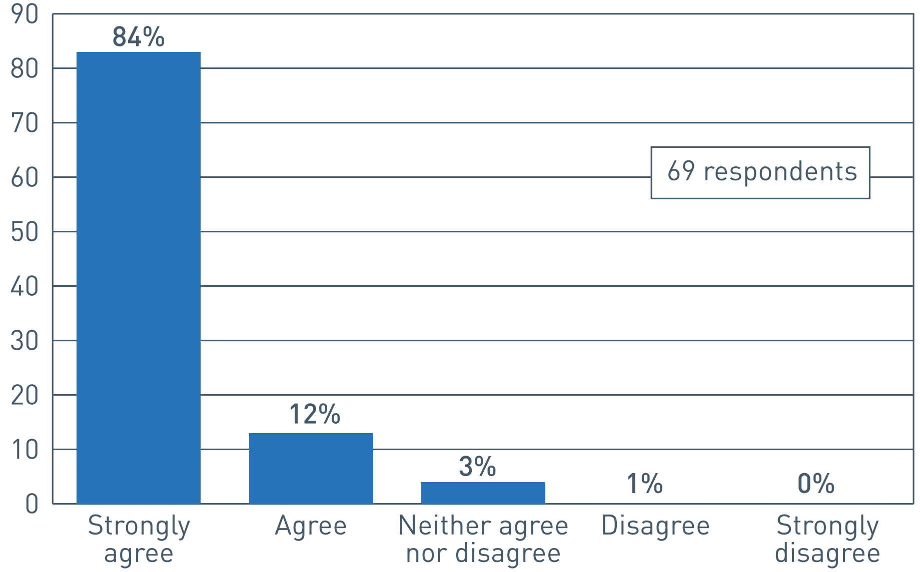
3. Life Opportunities

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

We want to ensure that people with autism feel supported throughout their whole life journey to lead meaningful lives, feel safe, protectected, valued and included



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”

Difficulties associated with the geography area as services are centrally provided

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

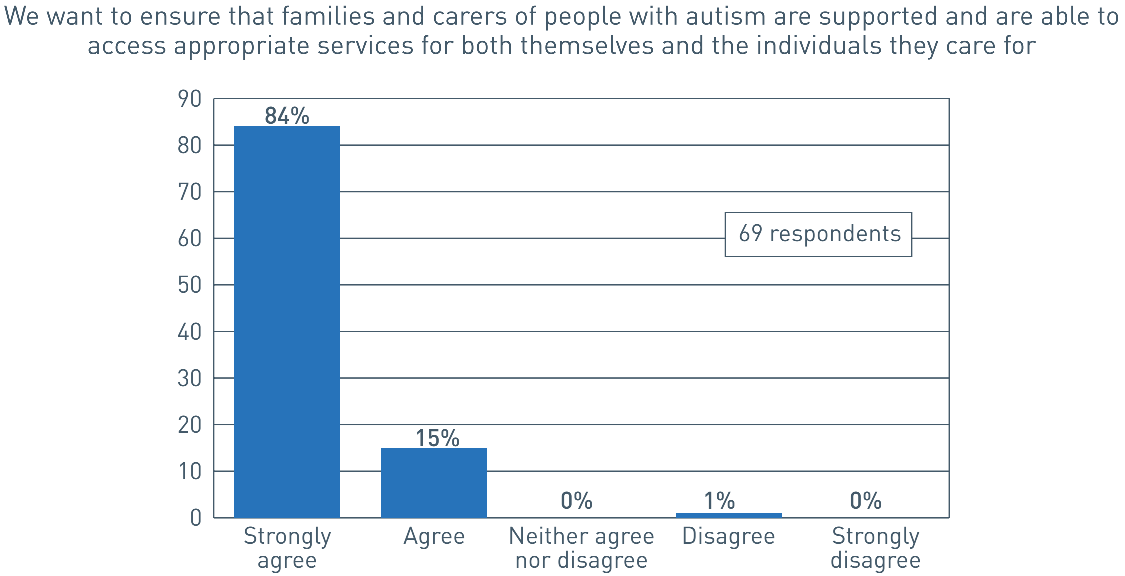
“Development of support groups in outlying areas?”

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.

Figure 4: Responses to Question 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"

"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”

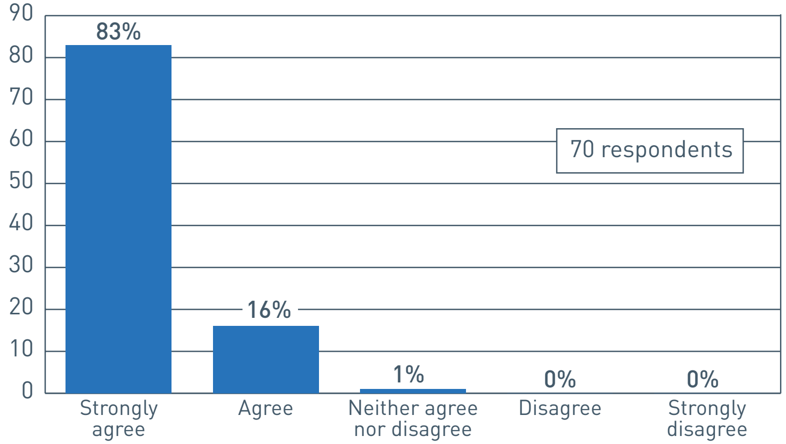
5. Information and Awareness

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

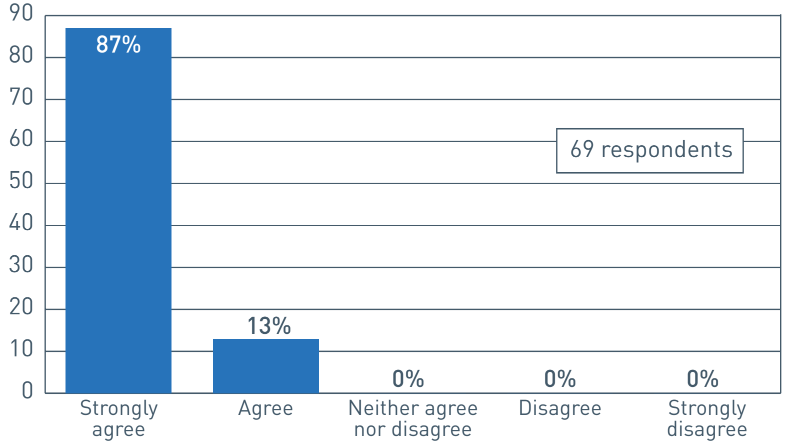
We want to ensure that people, their families and carers and professionals are able to access clear advice and information on local resources



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

We want to raise awreness of autism amongst professionals and the general public



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”

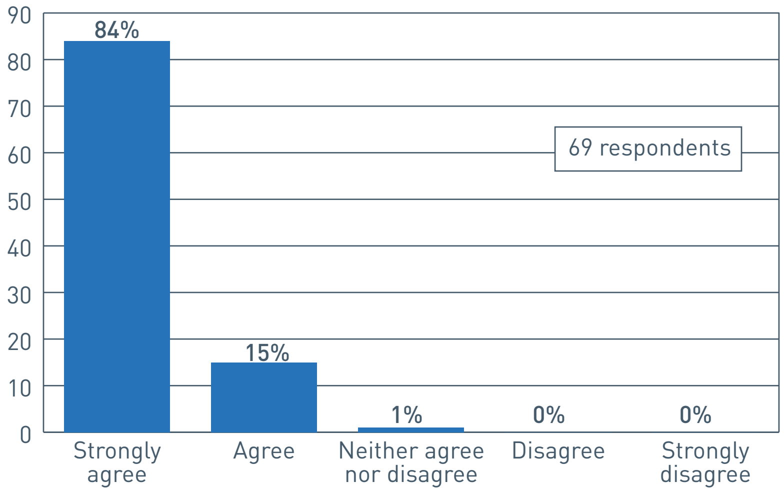
6. Transitions

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.

Figure 7: Responses to Question 7

We want to improve tranitions for children and adults with autism throughout the whole life journey



"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"

"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.."

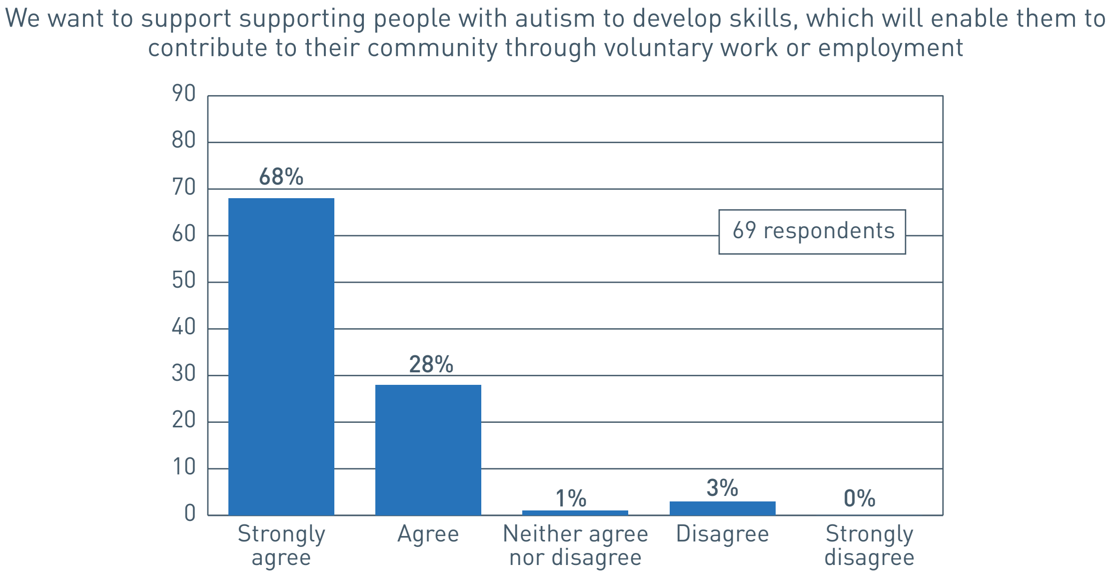
"Ongoing inclusion is essential, but must be appropriate and meaningful to the individual."

"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."

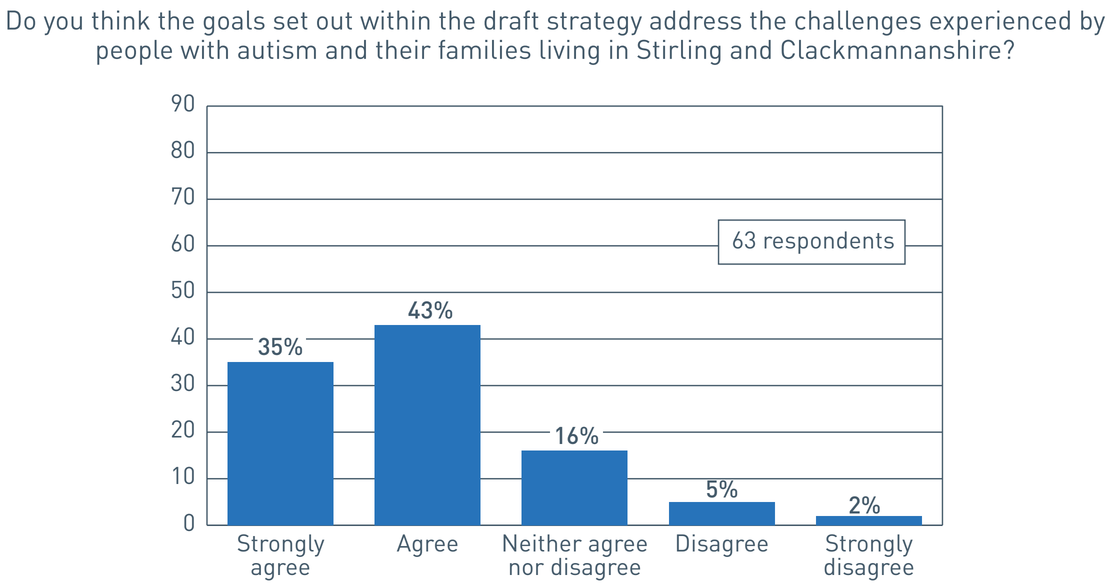
Figure 8: Response to Question 8



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.

Figure 9: Response to Question 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.

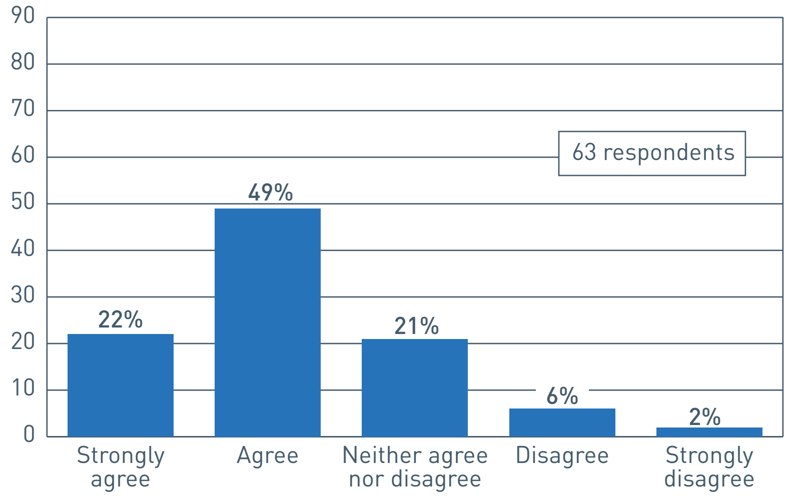
9 Are the strategy objectives appropriate to meet the local goals?

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.

Figure 10: Response to Question 10

Do you agree that the key objectives set out within the strategy will ensure our local goals are met?



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”

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.