



Warwickshire All Age Autism Strategy – Results of Phase Two Consultation

December 2013

Introduction

During the Spring of 2013, Warwickshire County Council launched a major public consultation to help find the best ways to support people living with autism and their families. The aim was to get as many people as possible fully involved in the in-depth consultation, which will inform and shape a new three-year 'All Ages Autism Strategy' for the county. A variety of consultation tools were used to encourage people to contribute their views and aspirations, including an innovative creative consultation element that helped young people share their opinions.

Following the analysis of the consultation, a second engagement exercise was undertaken, Phase Two, to ensure the information received from the first consultation had been understood and interpreted correctly. Two versions of the Phase Two consultation were made available, a full version and an easy read version.

This report summarises the responses received from the two questionnaires of the Phase Two consultation. The Phase One and Phase Two consultation results will be used to develop a strategy that puts people, rather than processes, first and channels available resources where they are most needed.

The 2nd consultation ran from mid-October until end of Nov 2013, and we received a total of 108 completed questionnaires. A profile of the respondents to each survey can be found at the back of this report.

Strategic Objective One – Develop a clear and consistent pathway including offer of support following diagnosis



The overarching themes that emerged from the first phase of the consultation were:

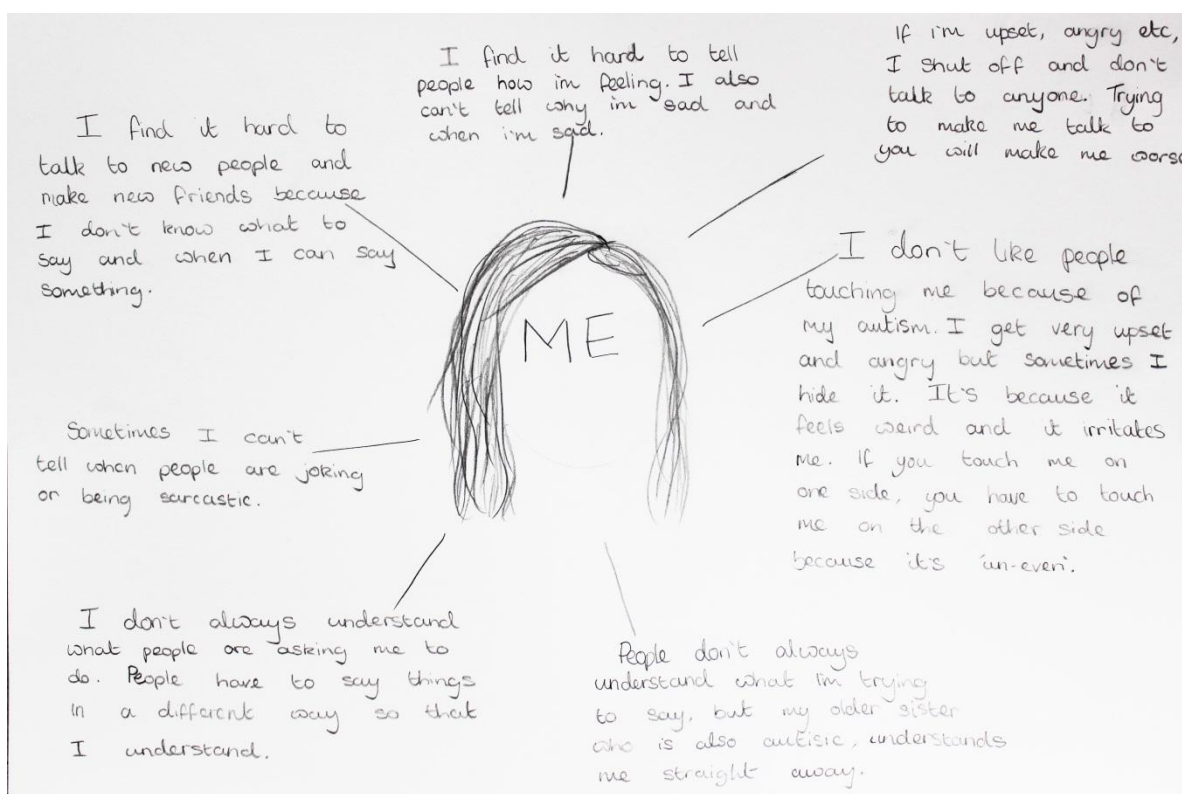
- Obtaining a diagnosis of autism is not straight forward or easily accessible and when referred for diagnosis the process takes a long time.
- Many professionals do not have the required knowledge and skills to accurately identify and signpost individuals for diagnosis. More defined earlier diagnosis pathway is needed with a step by step guide in an accessible format.
- There is very little support available post diagnosis.
- Diagnosis should be a transparent process and involve everyone connected to the person with autism.

From the second phase consultation, 89% agreed that their views had been interpreted correctly, a selection of comments from respondents are displayed below:

“Most of the above relates to post-diagnosis. The speed of diagnosis is a huge issue so perhaps an emphasis on the pathway through it needs to be addressed more fully, e.g. raising awareness in schools so that the warning signs are more easily recognised and acted on more quickly, rather than assuming a child is just badly behaved. A misunderstood autistic child's behaviour often has a negative effect resulting in a downward spiral of behaviour and more stress and anxiety for everyone involved.” – Parent / Carer

“There should be a clear pathway to information and advice as soon as a diagnosis has been made, either delivered by an autism 'champion' or through visual information to take away so that the individual(s) can access the support they need when they are ready.” – Parent / Carer

Strategic Objective Two – Increasing awareness and understanding of autism



The overarching themes that emerged from the first phase of the consultation were:

- All staff working in educational settings, not just teachers and learning support assistants need to be autism aware
- Autism training sessions need to include information and techniques on how to support with people who have sensory and behavioural issues
- Involve people with autism and families in raising awareness and educating staff about autism
- Training parents of children with autism to be better equipped to support their child in the family setting
- Parents of people with autism should be able to talk to other parents about autism
- Raising awareness needs to be an integral part of education and training for all frontline staff

From the second phase consultation, 91% agreed that their views had been interpreted correctly, a selection of comments from respondents are displayed below:

“Parent training sessions need to be continued long term, we had a lot of initial support when my son was first diagnosed at the age of four but have had nothing now since he was seven or eight, he is now seventeen! Feel slightly alone and abandoned when times are hard.” – Parent / Carer

“Make sure that support groups exist to offer help and advice to parents and carers of people on the autistic spectrum. My parents found that participating in a local support group was extremely helpful.” - Someone who has autism / Aspergers

“It is important that information is passed on from one teacher to another when the child moves class. Our experience was that each had to be referred to the report on own son's file explaining his difficulties in processing speech. Otherwise we would get comments such as ‘he needs to contribute more in class’. The planned action otherwise seems comprehensive.” – Parent / Carer

Strategic Objective Three – Education Learning & Employment



The overarching themes that emerged from the first phase of the consultation were:

- Buddying support networks should be available in all schools and colleges for people with autism who experience bullying.
- All children and young people should be educated about autism.
- Create 'autism friendly environments' in schools and colleges eg: respecting hypersensitivities, having flexible timetables and designated 'quiet places'.
- There needs to be more emphasis on social skills development and 'skills for life' training programmes in education settings.
- Opportunities for local work experience placements and apprenticeships leading to permanent employment.
- Many employment agencies and employers lack autism awareness and the skills to provide the right kind of advice to support people with autism into employment.
- Need to train and educate employers about autism, so that they understand the skills and strengths people with autism have to offer.

- Employment Mentors are needed to support people with autism to feel confident in finding and retaining employment.

From the second phase consultation, 90% agreed that their views had been interpreted correctly, a selection of comments from respondents are displayed below:

“Social skills and life skills (i.e. planning ahead, food preparation, housework, organising) are two different areas and autistic individuals struggle to learn these basics which are often overlooked. My son did not need higher learner opportunities, a few basic cooking, sewing, simple organisation may have been of more benefit, and stopped him from dropping out of University. I have enquired about 'buddying' at several Universities and the only one of six I asked who was able to offer this was Southampton! It is not available at the school my youngest child attends.” – Parent / Carer

“Social skills training are extremely important for young people in schools. Too often schools refuse to offer this training citing lack of money or time when it is one of the strategies that will make a huge difference to that individual's ability to cope socially. Bullying will only be dealt with effectively if a member of staff is out in the playground actually monitoring play activities and intervening to show how to 'play' more co-operatively and in a more inclusive way. Active and involved playground intervention is required at every playtime; it is of no use to have one adult 'monitoring' a whole playground whilst not seeing what is happening within groups of children and not intervening in a pro-active way.” – Parent / Carer

“Sometimes school and college isn't the right thing that a child/young adult needs. Some sort of 'buddy' support would be useful as well to help with support in other aspects of life.” – Parent / Carer

“This all sounds very good, however when young people with autism have been through a tough time at school they are sometimes very reluctant to go back into education as they cannot see past their previous experiences so early intervention is key! This needs to be considered especially for young people with Asperger syndrome and High Functioning Autism as these young people can often see and realise that they are different and this is when they find it extremely hard to cope.. By raising awareness before they enter secondary education would really benefit this group of young people. If they felt that there was someone who understood them and they had somewhere to go they may not crash and have meltdowns that they cannot control.” – Someone who works with people with autism

“Buddying systems and circles of support should be used in schools and colleges. An Occupational Therapy role should be made to support adults with Autism to get into work...the OT could assess a work place environment and recommend changes and adjustments to support the person to stay in their job.” - Someone who works with people with autism

Strategic Objective Four – Transition Into Adulthood



The overarching themes that emerged from the first phase of the consultation were:

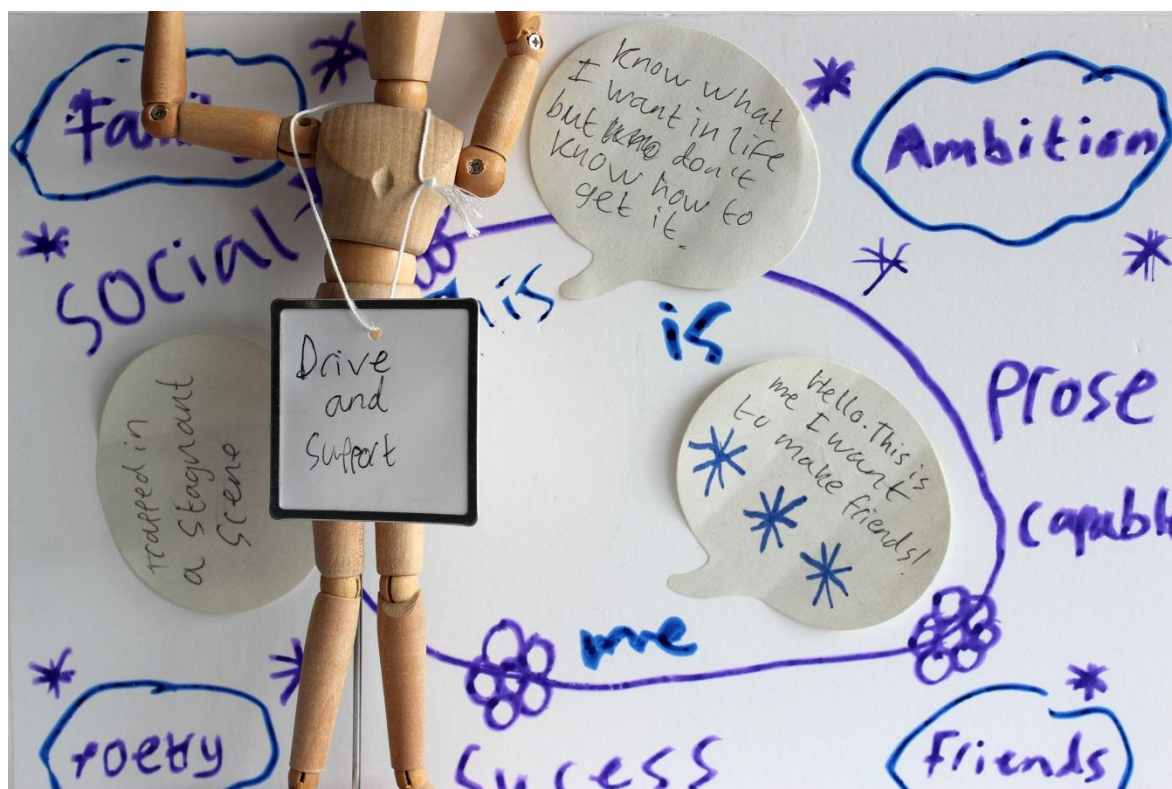
- There needs to be better partnership working for the transition from one education provider to another for people with autism of all ages; for example, mainstream to post 16 education settings. This should involve parents, health, social care and education.
- Lack of communication from agencies and no offers of support post education.
- There is no clear transitions pathway for people to follow.
- Transition plans need to be clear and realistic, ensuring consistency and continuity for people with autism and their families.
- Planning needs to start early and be a phased transition.
- Offer of peer support/mentors from individuals with autism who have already been through the process.
- There needs to be a multi-agency equal partnership approach including person with autism, their family and relevant professionals

From the second phase consultation, 93% agreed that their views had been interpreted correctly, a selection of comments from respondents are displayed below:

“This needs to be easily accessible and understandable for parents, transition is a very stressful time for all parties involved and we don't need to be bogged down with lots of needless information, keep it simple with the essential information made very clear.” – Parent / Carer

“Just start the process as early as possible.” – A person with Autism / Aspergers

Strategic Objective Five – Access to Services and Support



The overarching themes that emerged from the first phase of the consultation were:

- It is important to have an assessment of needs conducted by specialist staff.
- Those people with autism and their families who do not meet FACS (Fairer Access to Care) eligibility criteria for social care, should be supported to set up social enterprise models of services and support.
- As well as providing support for the child with autism, the needs of the whole family should be considered.
- A central point for information and advice on services & support.
- Work in partnership with people with autism to design and monitor services.
- Mentoring schemes involving people with autism to work with people with autism to develop life skills, including money management.
- Support parents to set up local support networks within the community.
- Child care providers need more training and support in providing preschool and afterschool care to children with autism.

- Many people who deliver services lack awareness or knowledge of autism. This leads to a poor service or no service.

From the second phase consultation, 92% agreed that their views had been interpreted correctly, a selection of comments from respondents are displayed below:

“This plan appears to be clear and appropriate. I am especially pleased to see that those not meeting the FACs will still have access to some support, especially at times of crisis. However, this support MUST be timely and appropriate.” – Parent / Carer

“All services must be much more widely available and advertised as I had no idea what services were available and some were only available in Warwick area not Nuneaton.” – Someone who has autism / Aspergers

“It is very important to provide a level of support that a person can access at times of need. Sometimes, the need can be quite small - starting to feel anxious about a particular task, for example - and if they knew there was somewhere they could go to get the support they needed at this stage then it would often prevent the need for crisis support. This would benefit everyone both in terms of reducing stress for the individual and financial for the Council.” – Parent / Carer

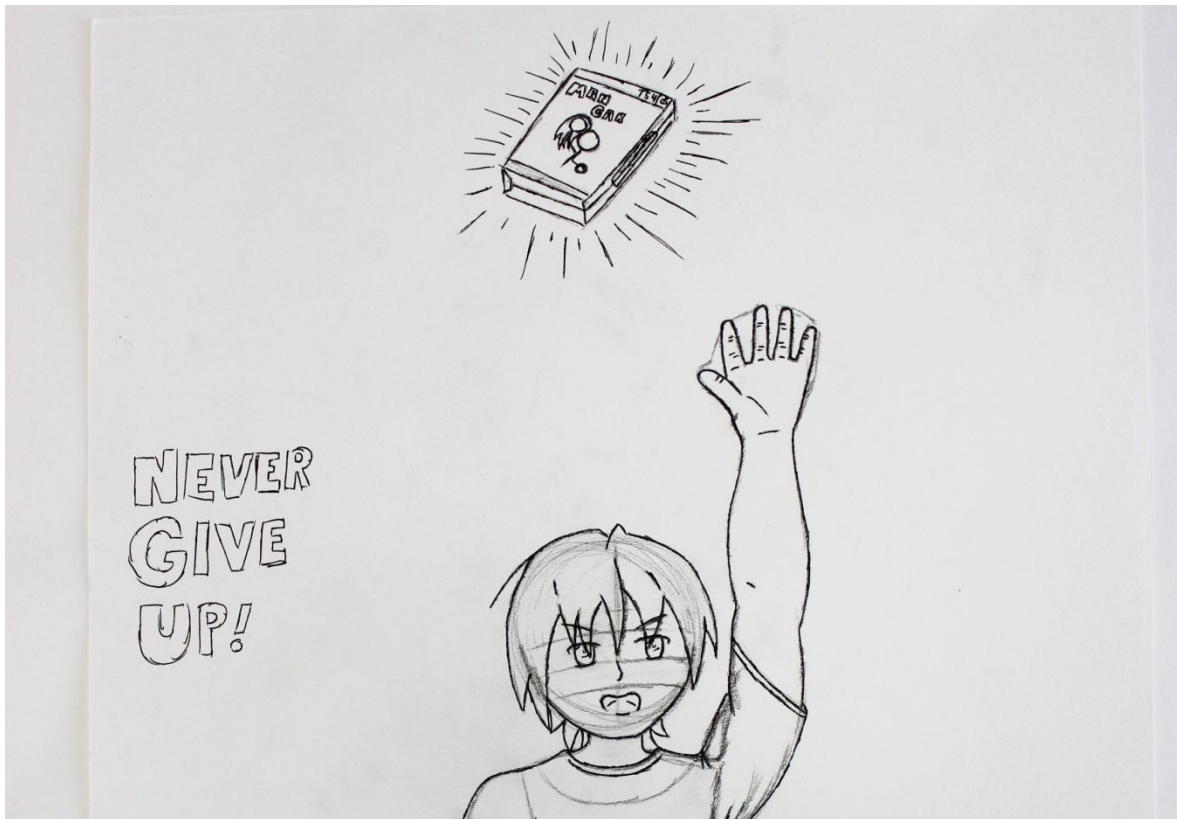
“Again, supporting people in a person centred way, to support individuals independence.” – Parent / Carer

“I think the range of services available look to be quite comprehensive. As a parent of a child with autism however I don't know about many of them. Perhaps more thought should be given to informing people at point of diagnosis then updating them via the database of new services as they become available. There's no point on spending money on services that no-one knows about.” – Parent / Carer

“Advocacy/mentoring scheme sounds brilliant.” – Parent / Carer

“Make more services readily available to families, and ensure you are letting all families know about events in their area for the family.” – Parent / Carer

Strategic Objective Six – Community Life (Social Inclusion)



The overarching themes that emerged from the first phase of the consultation were:

- Mentoring scheme is needed to support people with autism to access social and leisure opportunities within their local community.
- Wider community understanding of autism is required. This leads to acceptance of differences.
- Important to develop and foster good social friendships & relationships outside of the family.
- People with autism need to have the opportunity to socialise with non-autistic people.
- Social inclusion for those people with autism who live in rural areas should be considered as well as the provision of limited public transport.
- More autism friendly social events & clubs are needed.

From the second phase consultation, 87% agreed that their views had been interpreted correctly, a selection of comments from respondents are displayed below:

“More TV programmes to include people with autism?” – A group of children at a non-mainstream school

“It is important that social groups have an understanding of autism but are mixed. It helps the person with autism feel accepted and part of a mixed community, rather than segregated, and it helps other people learn and build up tolerance and understanding for a wider range of differences. We are all different and we need to live in a world where 'difference is the norm'.” – Parent / Carer

“Access to a social networking group where I could meet both others with autism and supportive non-autistic people would be of great benefit to me. This would hopefully allow me to make new friends and expand my social life.” – Someone who has autism / Aspergers

Strategic Objective Six – Community Life (Housing Support)

The overarching themes that emerged from the first phase of the consultation were:

- Information and advice on housing options should be readily available including financial advice and support.
- Clear information and advice given during the transition process, to support early planning for housing.
- Recognition of transport issues for people with autism including consideration of rural transport routes as this can create barriers to accessing services and support.
- When exploring housing options for people with autism, the location of local services and support is an important factor which needs to be considered.
- Support for families when the person with autism chooses to stay at home or needs to remain within the family setting.

From the second phase consultation, 94% agreed that their views had been interpreted correctly, a selection of comments from respondents are displayed below:

“Support needs to be on-going after any move to new / different housing. Difficulties are not always apparent at first and I would suggest that support is only gradually withdrawn as the individual gains confidence and experience. An emergency helpline needs to be available 24/7.” – Parent / Carer

“We live in a rural location with virtually no bus service. The one regular bus service we had has been axed because of the cuts. If my son doesn't drive when older how can he ever be independent if he has to rely on me for transport.” – Parent / Carer

“It is important that housing needs are considered from an individual's perspective rather than a planning or housing department. Individuals want to be able to live an independent life, they just need to be able to access support on site or nearby.” –

Parent / Carer

“I think it's a good idea to provide support for people who wish to live independently. I live with my parents and they are happy for me to stay with them for as long as I need, but I know they are concerned about what happens when they are no longer around.” – Someone who has autism / Aspergers

Strategic Objective Six – Community Life (Keeping Safe)

The overarching themes that emerged from the first phase of the consultation were:

- Wider publicity is needed for the Autism Alert Card and Safe Places Scheme.
- Improving public awareness of autism, including how it presents and what can be done to support individuals.
- Children and young people with autism do not always recognise unacceptable behaviour in others and this leaves them very vulnerable.
- Use the internet to educate children and adults with autism on how to keep safe.
- All emergency services, including police & people who work within the Criminal Justice System to have awareness training in identifying and supporting people with autism.
- Teenagers and young adults want and need social contact with peers of their own age. They don't generally want to be seen out with mum or dad. A scheme to get volunteers through schools and colleges as 'buddies' would be good.

From the second phase consultation, 97% agreed that their views had been interpreted correctly, a selection of comments from respondents are displayed below:

“This all sounds very positive.” – Parent / Carer

“This again comes down to educating young people to accept difference and embrace young people with autism for being different. Autism awareness cards are useful and will help though not all young people will want to carry them so again awareness is key. Training is paramount to improving local services.” – Someone who works in the field of Autism

“Again, mentoring or a buddy scheme would also be invaluable.” – Parent / Carer

“I have some Autism Alert Cards and I feel happier that they would explain my condition should I need them. Hopefully if needed, e.g. if stopped by the police, the police officer would be reasonably aware of the condition and how it affects people.”

– Someone who has autism / Aspergers

Strategic Objective Seven – Supporting Carers and Families of People with Autism



The overarching themes that emerged from the first phase of the consultation were:

- Family involvement in meetings with other organisations, including social care and health professionals.
- Carers need to be listened to and acknowledged and respected as an expert for the person they care for.
- Siblings need support to help them understand some of the challenges of having a brother or sister with autism. As well siblings being able to have quality time with parents and other social contacts.
- More timely support, information and advice available for a family maybe a buddy system for carers.
- More local parent/carer support networks are needed so that parents can have a break from caring and get together socially with other carers.
- Breaks for carers are so important. Respite services should be planned or available in an emergency. Getting the support right for carers often relies on getting the support right for the person with autism so the carer is freed

up to take the break they need, therefore whole family assessments of need are required.

- Parents need someone to talk to about what having an autism diagnosis means so they can understand the diagnosis and prognosis and the support available to them.
- Having more information and access to carers assessments and services and support would help in my caring role. Some carers do not know what they are entitled to under carers legislation and need the opportunity to reflect upon their caring situation and talk about this with someone that can help guide them to the right support.
- Carers are concerned about what will happen to their relative when they themselves can no longer provide this care

From the second phase consultation, 95% agreed that their views had been interpreted correctly, a selection of comments from respondents are displayed below:

“A lot to implement - but please, please try.” – Parent / Carer

“Following diagnosis please make help available immediately. The despair we all felt after our son's diagnosis only to be told now go home and wait four months for a place on the early bird program. The wait was unbearable, the darkest days of our lives.” – Parent / Carer

“Help needs to be made available to carers of people with autism. I still very much rely on my parents and my mum gave up work when I was younger to make sure I was adequately cared for and supported.” – Someone who has autism / Aspergers

“The provision of local support groups to enable people with autism to meet with similar aged non-autistic people is essential if we are to develop a degree of independence. The opportunity to meet others with autism who have already made some of the difficult choices facing me would be very helpful.” – Someone who has autism / Aspergers

In addition to implementing the WCC Carers Strategy, the first phase of the consultation also identified additional issues for carers:

- Ensure that the work to develop post diagnostic support services takes into account carers needs for information, advice and support. Carer assessments should form part of this support and it needs to be considered where best this should take place and who should conduct these assessments so that carers are not repeating themselves and get the right support at the right time by those best skilled to assess and advise them.
- Ensure there are a range of short break services are available to people with autism who may wish to purchase their own service/support using a Direct Payment.
- Offer co-productive opportunities for family/parent carers and people with autism to become members of the Transformation Assembly or Autism Partnership Board.
- Ensure information is made available in regard to the young carers/siblings support service.
- Encourage and stimulate the development of peer support networks and mechanisms for sibling support.
- Ensure there is clear and concise information available following a diagnosis and across the caring journey accessible in a range of formats.
- Stimulate the development of training for carers of people with autism and that this is led using the 'experts by experience' approach.

From the second phase consultation, 93% agreed that their views had been interpreted correctly, a selection of comments from respondents are displayed below:

“The plan sounds okay but I would like the chance to have more of a social life but not always with a disability group. It would help to have a list of groups/societies/organisations that I could possibly join - I would even consider travelling to other areas of Warwickshire but it's knowing what's out there. I haven't found anything on the internet.” – Someone who has autism / Aspergers

Anything else

Finally, respondents were asked if there was anything else that they would like to mention. Although most respondents agreed with the Strategy, the following concerns and issues were raised within the consultation responses:

- Over-reliance on voluntary groups
- More work needs to be done on social inclusion
- Better promotion of services
- Better transition planning
- Generally more support is required, particularly post-diagnosis

A selection of comments from this section are displayed below:

“There is an awful lot of aims and plans and work here. It’s all very positive and constructive but making it happen and making it real - so it really benefits autistic people’s lives - and their families - will be a long and challenging battle. Please, please try and implement as much as possible - anything that helps us, please attempt to put in place, life is very hard with autism and a lot of families break down and are very stressed and over - stretched and therefore unhappy places for everyone to live in? Thank you for your hard work. Good luck.” – Parent / Carer

“I think you have done a great job in drawing together numerous strands within the field of autism. It would be good to see how these are implemented over the next few years, invest to save must be the adopted mantra especially when resources are being squeezed in all service areas. I am concerned about the reliance on a voluntary sector. This can work but it needs a very tight commissioned lead with paid professionals to over-see quality and consistency of input.” – Parent / Carer

“It’s a brilliant plan that will hopefully help with my son’s disability anything that makes people more aware of autism is a good thing, and so that he can feel confident that there are people that will help him in all stages of his life.” – Parent / Carer

“The constant stress of having to seek out information, agencies which can provide services and /or support and ensuring you receive what you are entitled to either for the person with ASD or yourself as a carer is debilitating. It takes up huge amounts of time and energy and that is on top of all the demands of caring. I still battle to get the basic levels of support and when I get things in place I find the goalposts have been moved and I start again! Everyone needs to be reading from the same script and moving things along at a pace to ensure that needs are being met quickly and support is there to avoid breakdowns and the creation of more difficulties.” – Parent / Carer

Respondent profile

	Characteristic	No. of
Gender	Male	19
	Female	64
Age Group	Under 18 years old	3
	18 – 29 years old	7
	30 – 44 years old	28
	45 – 59 years old	34
	60 – 70 years old	8
	71 – 79 years old	4
	80 years and older	1
Disability / situation	Someone who has autism / Asperger Syndrome	16
	Someone who has a learning disability / difficulty	7
	Someone who has a mental health problem	9
	Someone who has a physical disability	4
	Someone who has a long-standing illness	7
	Someone who has a terminal illness	0
	Someone who has sight or hearing loss	3
	Someone who has dementia	0
	Someone who has problems connected to ageing	3
	Someone who feels they may be misusing alcohol or	0
	Carer of a child	27
	Carer of an adult	24
	Someone who works in the field of autism	2
Borough / District of residence	North Warwickshire Borough	10
	Nuneaton and Bedworth Borough	12
	Rugby Borough	7
	Stratford-on-Avon District	17
	Warwick District	34
	None of the above / Don't know	4