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### Warwickshire Autism Strategy – Results of a Consultation with Adults, Young People and Children

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August 2013

## Introduction

During the Spring of 2013, Warwickshire County Council launched a major public consultation to help find the best ways to support individuals and their families with autism. 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.

1 in 100 people – children and adults – live with autism in the UK and there could be many more who have not been diagnosed.

This report summarises the responses received from two questionnaires, one targeted at children and young people aged 16 and under, and the other at adults. These consultation results will be used to create a Warwickshire definition of autism. They will also be used to develop a strategy that puts people, rather than processes, first and channels available resources where they are most needed.

The consultation ran from March 4<sup>th</sup> 2013 until May 31<sup>st</sup> 2013, and was aimed at children and young people and adults living with autism (whether diagnosed or not), carers, service providers and professionals.

The adults survey received a total of 268 completed replies, whilst the young people's survey received 75 completed replies. The first section of this report analyses the responses from the Adults survey, whilst the second section analyses the results of the survey to children. A profile of the respondents to each survey can be found in Section 3 of this report.

## Section 1 - Adults Survey

### Section 1.1 – Autism Definition

The National Autistic Society says that autism is:

"A lifelong developmental disability. It is part of the autism spectrum and is sometimes referred to as an autism spectrum disorder, or an ASD. The word 'spectrum' is used because, while all people with autism share three main areas of difficulty, their condition will affect them in very different ways. Some are able to live relatively 'everyday' lives; others will require a lifetime of specialist support."

Respondents were asked if there was anything else to add or change to the statement to strengthen it and make it a Warwickshire meaning to autism. A number of respondents did not think that a local definition was required, of those that gave further suggestions to strengthen the statement, the table below summarises their responses.

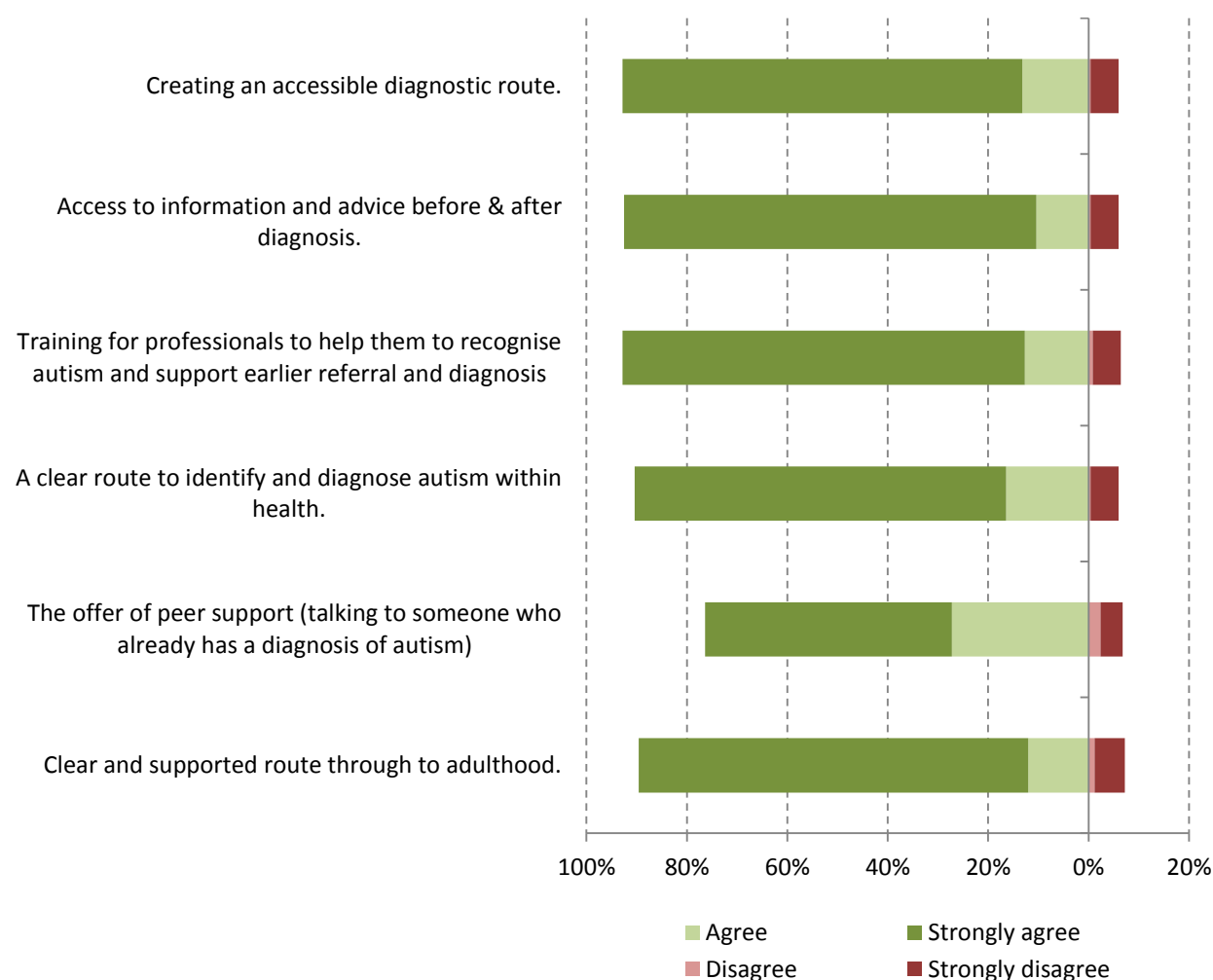
Theme / Issue	No. of comments
Specify the three areas of difficulty	15
There is a spectrum, and sufferers should be treated on an individual basis	10
Specialist, on-going support is required	10
It is a 'hidden disability'	9
Include something on sensory needs / difficulties	8
Include something on a lack of social and communication skills	8
It is a lifelong condition	5
Difference, not disability	5
People with autism need a routine	4
Experience high anxiety levels	3
Unable to stay calm	3
It is a neurological disorder / condition	3
Opportunity for an alternative perspective on the world	3
Can be very intelligent individuals	3

## Section 1.2 – Diagnosis and Support after Diagnosis

For many people receiving a diagnosis of autism is an important step in their life. It helps them and their families understand their behaviour and responses. It should also help with access to services and support, if they need them.

Respondents were asked how strongly they agreed or disagreed with a number of statements on diagnosis and the support they received following a diagnosis, Figure 1 shows the results. The majority of respondents agreed with all six of the statements below, with approximately 90% of responses strongly agreeing with each of the statements. The exception was the offer of peer support, to which 7% of respondents disagreed, and 17% neither agreed nor disagreed.

**Figure 1: Agreement with statements about diagnosis and support after diagnosis**



Respondents were also asked to make any further comments how diagnosis would work in Warwickshire; the table below displays the most common themes mentioned by respondents.

Of the 147 comments in this section of the questionnaire, 44 made reference to requiring more support, both throughout the diagnosis process, and following diagnosis. Many respondents also felt that more training was required to recognise autism, that the diagnosis process was too slow and that there should be more awareness about autism.

Theme / Issue	No. of comments
More support throughout and following diagnosis	44
Better training for staff inc. GP's, Teachers, Child minders	27
Diagnosis process is too slow	26
Multi-agency approach should be adopted	23
Generally more awareness of autism	21
More should be done to diagnose autism earlier	18
Clear pathway and transition between childhood and adulthood	18
Diagnosis should be easily / more accessible	16
Information packs are required	13
Diagnosis should be undertaken by a professional	12
Family should be more involved in diagnosis	10

“... Parents views on their child’s diagnosis need to be listened to. More information for nursery and school staff to spot signs of autism especially behavioural problems. Referrals to CAMHS need to be dealt with quickly. Once a diagnosis is given parents need support, advice and contacts to help them deal with a life changing situation. The more information the better. Advice about benefits available and how to fill the forms is important too. Emotional advice and support to be accessible.”

“Diagnosis can take a long time. There is some support available during this time but more support should be made available. Also the diagnosis process should be made quicker. Whilst assessment should be made carefully, with suitable checks in place, from my experience the diagnosis could have been made a lot quicker if inter-departmental communication within Warwickshire CC was more efficient.”

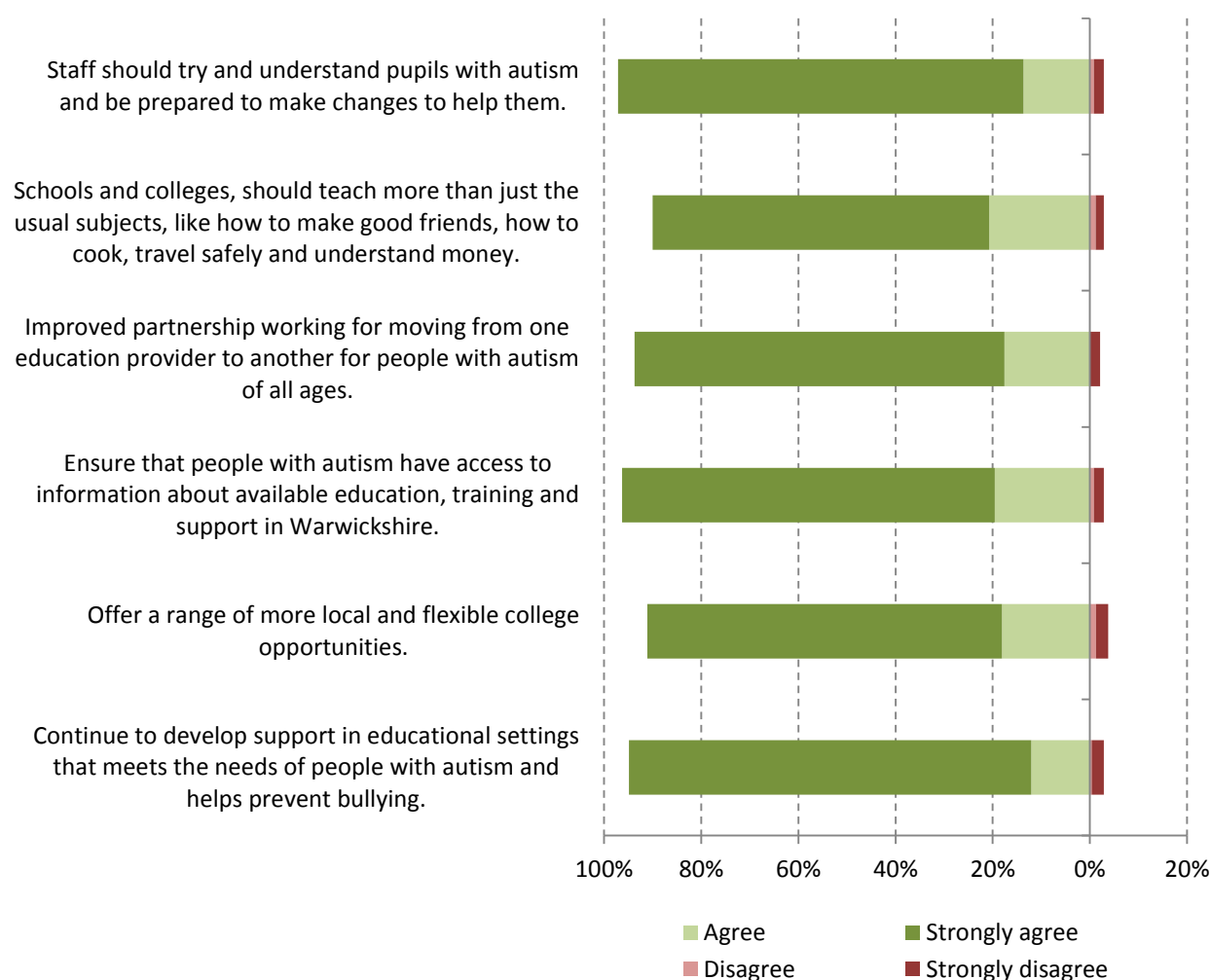
“For better training for educational workers to help and support the individual. More awareness for young people in schools, colleges for them to accept them in public.

## Section 1.3 – Education

People with autism should be able to make the most of their abilities by getting the same opportunities for education and further education as everyone else. Educational settings need to make reasonable adjustments for people with autism to reduce barriers to completing courses, gaining qualifications and the social aspect of college life. Transition planning should act as a route to access support in further and higher education.

Respondents were asked how strongly they agreed or disagreed with a number of statements on education, Figure 2 shows the results. The majority of respondents agreed with all six of the statements below, with approximately 90% of respondents ‘strongly agreeing’ or ‘agreeing’ with each of the statements.

**Figure 2: Agreement with statements about education**



Respondents were also asked to make any further comments about anything else that would make a difference to education; the table below displays the most common themes mentioned by respondents. Of the 157 comments in this section of the questionnaire, 48 commented that better training for staff involved in education was required. Many respondents also felt that more flexibility was required in schools, so that each young person with autism could be treated on an individual basis, and be provided with support that was bespoke to their needs. Other themes included further information and support for young people with autism, more awareness for other students and teachers and a tougher stance on the bullying of people with autism.

Theme / Issue	No. of comments
Training for staff involved in education	48
Flexible and individual support	42
Information and support to students	33
Awareness raising and information for students without autism	26
Act on bullying	15
Better transition from primary school to secondary school to college	12
An expert on autism to be available at all schools	12
More funding for specialist autism centres / schools	10
Early diagnosis	10
Better partnership working between schools and home / health authorities	7
Buddying / mentoring schemes	7

“Bullying is a big issue in schools for people with autism as they are an easy target. My grandson has had a terrible time at school and this needs to change.”

“Changing the perception of individuals within the education sector to appreciate that people with autism are able to successfully contribute to society. They are not simply nuisances who take some time to grasp the concept of learning, but are extremely productive people who can achieve great things if a little more time and effort were set aside for them ...”

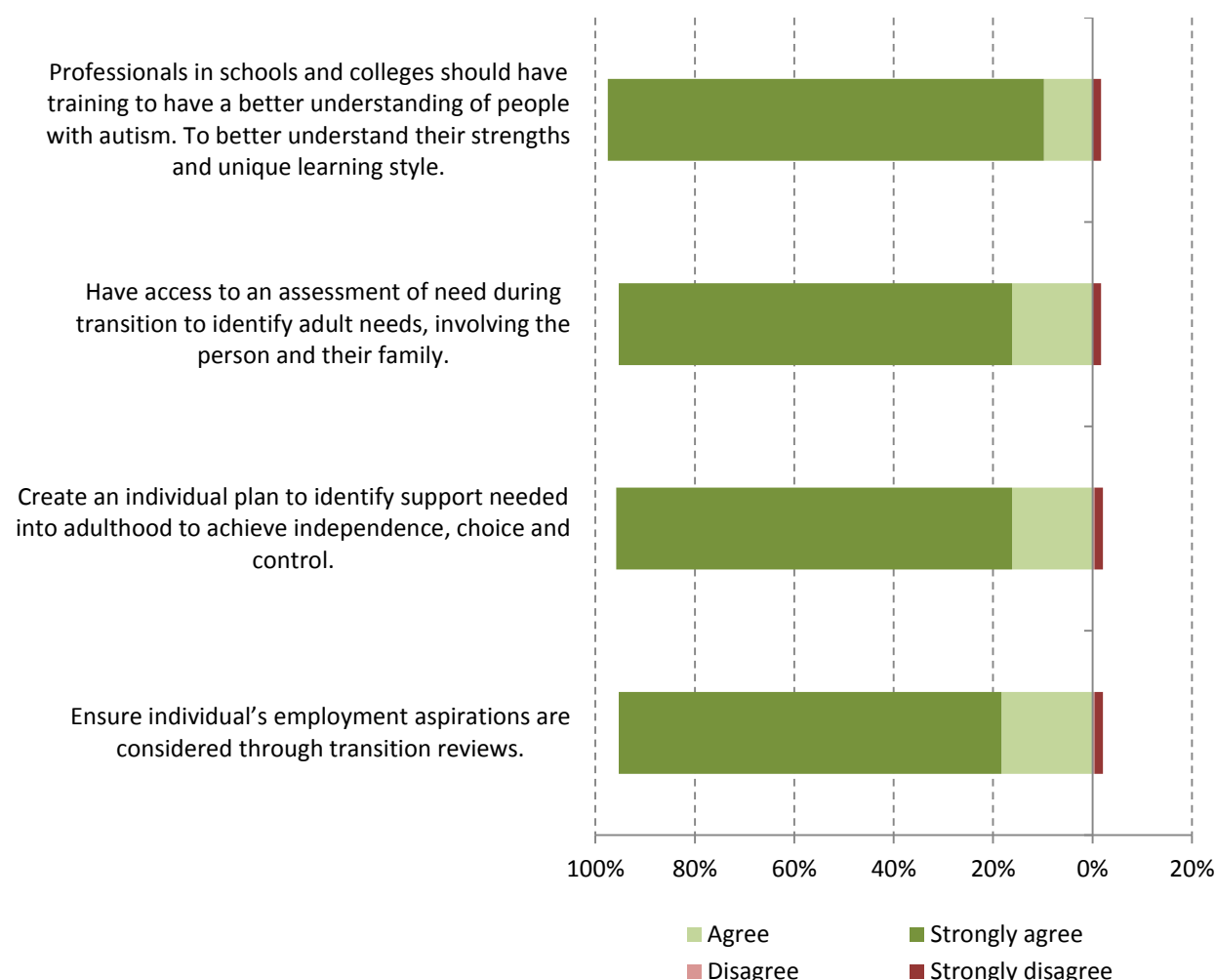
“Training for all staff in educational settings. An increase in the number of staff with experience, knowledge of Autism to provide free advice, support to educational settings.”

## Section 1.4 – Transitions

During transition, a young person is on a gradual continuum from being a child being cared for to becoming an adult, making decisions about their own life, with support, if necessary. The aim of the transition process is to minimise disruption, and to enable young people to realise their potential for independence.

Respondents were asked how strongly they agreed or disagreed with a number of statements on about their transition from a child to an adult, Figure 3 shows the results. The chart below shows that almost all respondents agreed with each of the statements; with on average just 2% of respondents in disagreement.

**Figure 3: Agreement with statements about transitions**



Respondents were also asked if there was anything else that would help the smooth transition into adulthood; the table below displays the most common themes mentioned by respondents.



Of the 116 comments in this section of the questionnaire, 31 made the general comment that more support was required. Many respondents also felt that more courses that helped people with social skills would help, as well as the range of authorities and organisations working together. Once again, a tailored approach to each individual was also mentioned, as well as honest, realistic and transparent plans for transition.

Theme / Issue	No. of comments
More general support on transitions	31
Courses on social skills / life skills	16
Multi-agency approach	15
Tailored to individuals own pace	14
Realistic / consistent / honest / transparent plans	14
Clear pathway / follow code of practice	11
Better training for people involved in education	9

“Having clear information about what to expect from the transition process and a clear time line of when each part is supposed to happen....then for it to happen as planned.”

“I think reassurance for parents and carers on how to prepare and what services are there for these children when they do reach an adult as looking after our children is filled with constant anxiety enough. Parents with "regular" children can assume that they will mostly make their own independent choices in life but with a disabled child you always have to be their voice and make every effort they get the support they are entitled to with little inside knowledge of how the system works.”

“Improved opportunities to take part in work experience whilst still at school. Life skills classes. Access to a wider range of social opportunities that are tailored to need.”

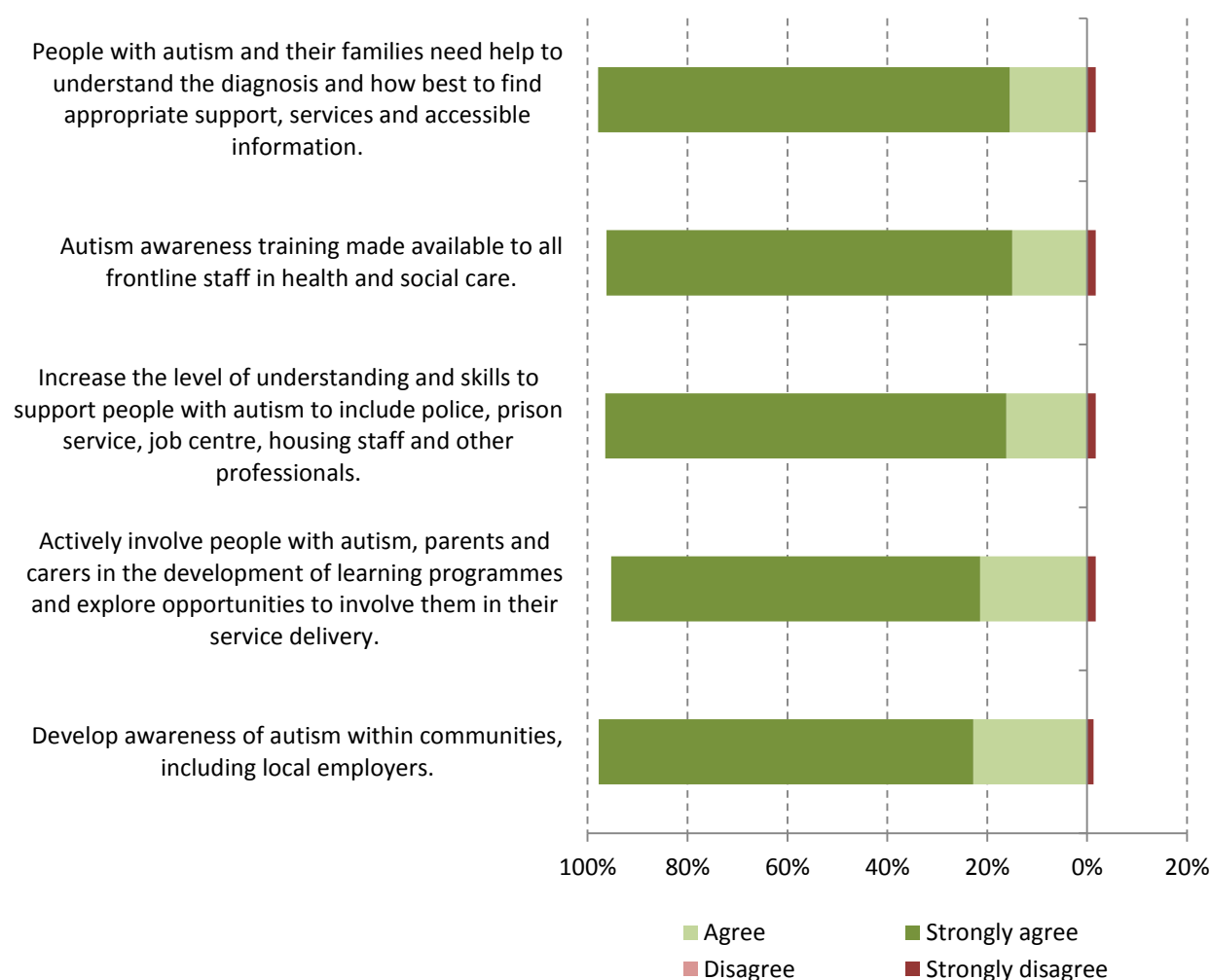
“Open communication between all stakeholders and realistic expectations given before process begins. A clear route/journey for families and customers would greatly reduce anxiety about the process.”

## Section 1.5 – Awareness and Understanding

It is essential that at the very least autism awareness training is available to everyone working in frontline services.

Respondents were asked how strongly they agreed or disagreed with a number of statements on about their awareness and understanding, Figure 4 shows the results. The chart below shows that, again, almost all respondents agreed with each of the statements; with on average 98% of respondents in agreement.

**Figure 4: Agreement with statements about awareness and understanding**



Respondents were also asked if there was anything else that would help increase the awareness and understanding of autism; the table below displays the most common themes mentioned by respondents. Of the 106 comments in this section of the questionnaire, 48 made general comments that society needs to be more aware and accepting of people with autism, including

the Police and employers. A number of respondents commented that information about autism needs to be made more accessible, whilst a similar number believe that an awareness of autism should be made part of the school curriculum. Twelve respondents also suggested that positive stories should be communicated to a wide audience to increase understanding.

Theme / Issue	No. of comments
Society needs to be more accepting and understanding	48
Information should be more accessible	14
Autism should be part of education curriculum	12
Positive / success stories communicated	12
Family should be involved to improve awareness	9

“Autism awareness needs to be taught to children at a young age. Tot groups could be approached by an autism specialist who could give information and advice to parents. Drop in centres would be ideal. Information about autism (posters leaflets) to be sent to sport centres, businesses, colleges, to help widen the awareness.”

“Autism awareness training should be 'sold' as necessary training to all emergency services, the police, courts [and other legal services], DWP/jobcentre, council departments, GP's and other professional services much as Deaf Awareness was some years ago. Autism affects so many people and should be recognised as being the disability that it is by those frontline professionals who should have a basic knowledge of the condition and how best to help anyone who they deal with. The training could be offered free where it was felt essential or for a fee to other agencies/professionals. It would be important to have those delivering the training sessions to have all had the same training themselves to ensure that the same information was being delivered at training courses.”

“For all the above to have training from people with ASD and their carers. For services to show their readiness to employ individuals with ASD.”

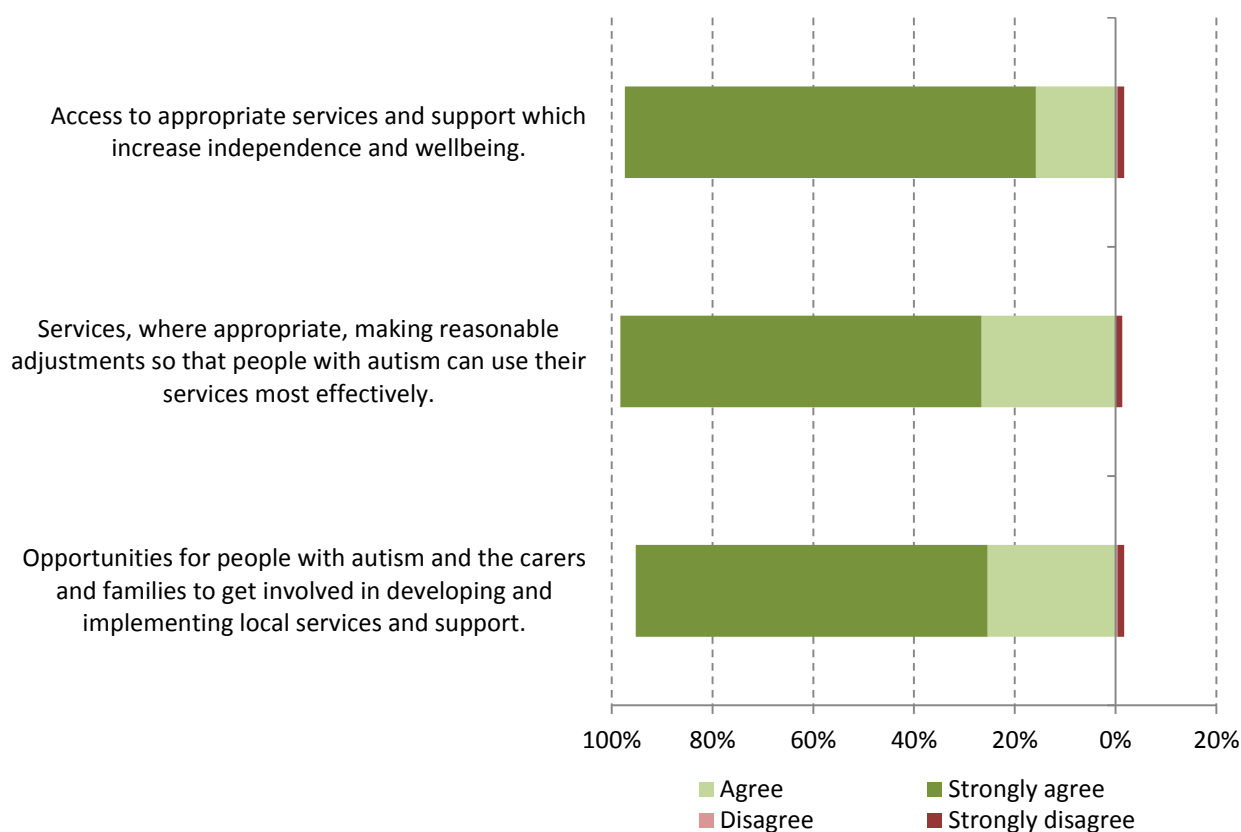
“How tricky this is! Any activities that are inclusive so that people realise how many guises the autism spectrum can come in. Parents, family should also feel confident about talking openly about it when appropriate so that even with Asperger young people awareness can develop not to be judgemental and that autism isn't just about non-communication but also covers the variety of quirkiness and eccentricities that goes with autism spectrum.”

## Section 1.6 – Access to Services and Support

Equality of access is a fundamental principle of UK public services, but too often, people with autism are not currently able to access the services and support they need. Following diagnosis, adults and children with autism will be entitled to an assessment to establish what levels and type of services and support are needed.

Respondents were asked how strongly they agreed or disagreed with a number of statements on about their awareness and understanding, Figure 5 shows the results. The chart below shows that, again, almost all respondents agreed with each of the statements; with on average 98% of respondents in agreement.

**Figure 5: Agreement with statements about access to services and support**



Respondents were also asked if there were any other services or support that was required; the table below displays the most common themes mentioned by respondents. Of the 99 comments in this section of the questionnaire, a wide range of comments were received. The most common theme was having access to trained health staff to provide one-to-one support. Social activities and courses were also seen as important, as well as respite care and support for

families. Having access to information and services in a timely manner and more effective signposting was also mentioned by 15 respondents.

Theme / Issue	No. of comments
Access to health professionals for one-to-one support	25
Social activities and opportunities / courses	18
Respite care / support for families	17
Easier access to services / better signposting	15
Help with housing / living independently	6
Better training for support services	6
Better training for families / carers	6

“Access to services must be enabled in a way which the person with autism finds easiest to use - e.g. using email rather than telephone. There may need to be some more proactive involvement from services to ensure that the person with autism has what they need, rather than assuming that non-access means that the service is not required. For some people there may need to be a "key worker" with whom a relationship can be built, who can help with access, to ensure that they are not dependent only on family.”

“Again all of the above should already be there. However, there is a great need anyone with Autism to have support as they need it. Again you ask about 'independence' but you have to realise most won't ever be in this position. Sadly there are too many people that still see Autism as an excuse for bad behaviour and poor parenting.”

“Support and respite for the family. Opportunities for the child to engage in society. Better services (free) available to the family. We have been very let down by the lack of support for us as a family, initially yes we were put on the parent course, but then left to get on with things, it has been quite frustrating.”

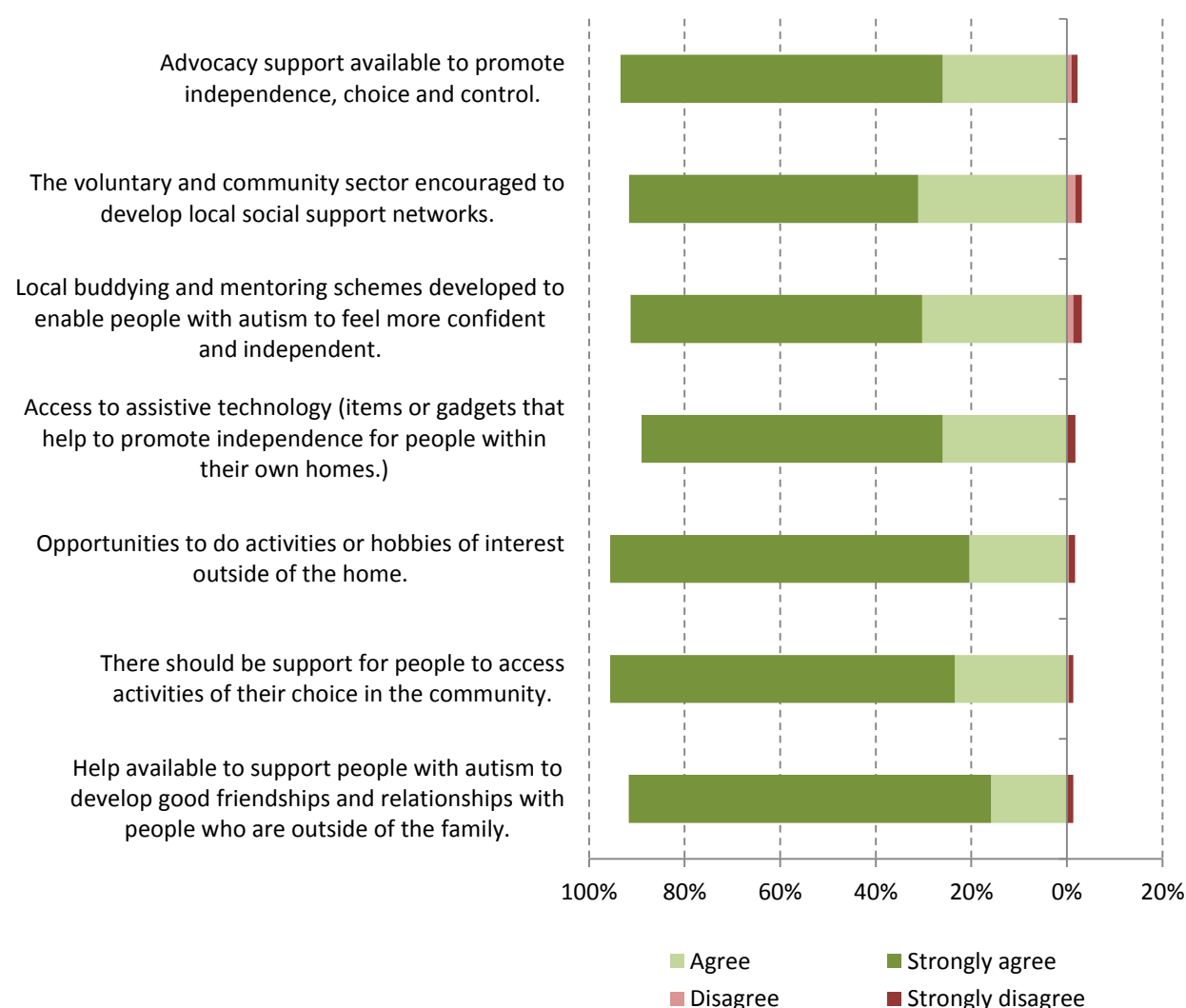
“This is about respect and independence. It is the autistic person who is at the centre of this and should always be involved.”

## Section 1.7 – Social Inclusion

All adults and children with autism are entitled to live fulfilling and rewarding lives within a society that accepts and understands them.

Respondents were asked how strongly they agreed or disagreed with a number of statements about social inclusion, Figure 6 shows the results. Again, there were very low levels of disagreement with any of the statements in this section of the survey.

**Figure 6: Agreement with statements about social inclusion**



Respondents were also asked what else was important to them about social inclusion, the table below displays the most common themes mentioned by respondents. Of the 115 comments in this section of the questionnaire, 35 mentioned that people with autism require activities and

courses that help them develop their life and social skills. A further 25 respondents mentioned that there should be more awareness and understanding of autism, in order to give people with autism a fair opportunity, whilst 12 respondents suggested that people with autism needed more opportunity to mix with non-autistic people, to help them feel 'normal'.

Theme / Issue	No. of comments
Social / life skills and activities	35
More awareness and understanding of autism	25
Need to mix with non-autistic individuals	12
Mentoring / buddying scheme	8
Flexible approach / tailored services	8
Voluntary sector networks	6
More information / signposting	5
Bring people with all types of autism together	5

“As the parent of a 17 year old with ASD who wishes to live an independent life in the future, I would like autism awareness to be promoted in such a way that any concerns regarding treatment of my daughter by others were not so huge ... Social inclusion should mean that all individuals with autism are made to feel welcome and as if they are part of whatever they choose to do in life, rather than a nuisance to people.”

“It is hard for autistic people to participate in social activities if the support and understanding of the condition is unknown. More activities for all ages geared at those with autism is needed. More access to sporting facilities and groups designed to accept autistic individuals.”

“It is very important to offer an advocacy service. People with autism need choice and control they also need somebody independent to fight their battles. There is a big need for more social activities to be made available for people with ASC or have them included in mainstream activities. Social activities and inclusion is an absolute must.”

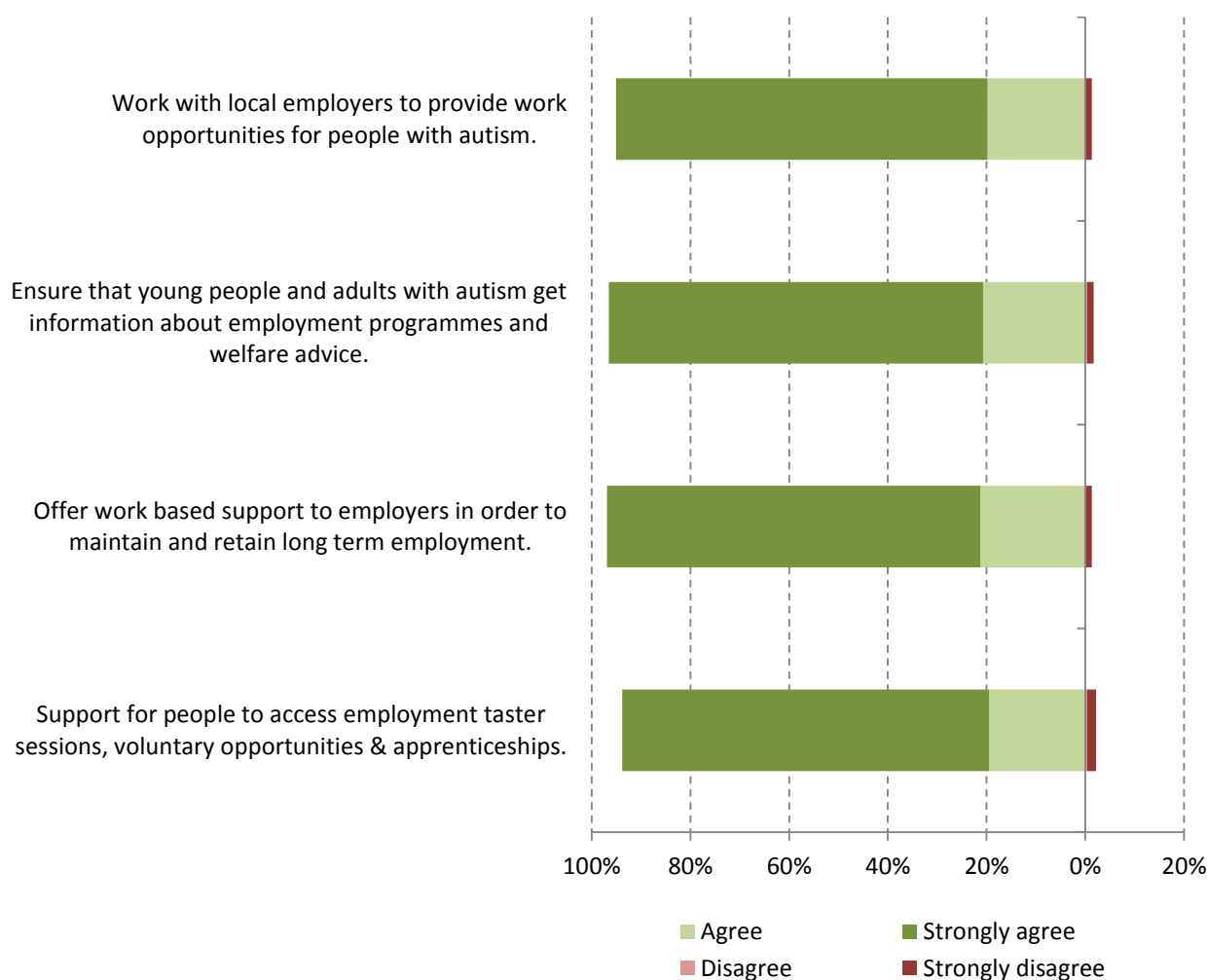
“Social inclusion is important but it needs to be specific to the individual. Social activities usually come at a cost and (for some individuals) can only be accessed with a paid worker, and indeed paying for that worker to participate whilst supporting them”

## Section 1.7 – Access to work

People with autism want to work and have skills and abilities that would be beneficial in the workplace. With practical support, advice and training, people can both get and keep a job. Employers also need information about how best to support a person with autism within the workplace.

Respondents were asked how strongly they agreed or disagreed with a number of statements about access to work; Figure 7 shows the results. There were very low levels of disagreement with any of the statements in this section of the survey, with approximately three-quarters of respondents ‘strongly agreeing’ with each of the statements.

**Figure 7: Agreement with statements about access to work**



Respondents were also asked what other services or support would help people to find and maintain employment, the table below displays the most common themes mentioned by



respondents. Of the 73 comments in this section of the questionnaire, the most popular theme of comment focussed on raising the awareness of employers and providing them with information about how to get the best out of people with autism. A mentoring / buddying scheme in the workplace was mentioned by ten respondents, whilst seven respondents suggested taster sessions or work experience would help the transition of people with autism into the workplace.

Theme / Issue	No. of comments
Raise awareness and provide support to employers	24
Mentoring / Buddying scheme	10
Taster sessions / Work experience	7
Job Centre advisers / career advisers need support	6
General support finding any kind of work	5
WCC / employers / Colleges to work together	5

“A buddy/mentor may well be needed every step of the way towards employment + probably for same time into a job.”

“Start in school with day release/work placements to build knowledge within the workplace about autism and what it means within employment. The young people would benefit and employers/employees would get invaluable experience. Offer potential employers Autism Awareness Training! Promote the benefits of an employee with autism! It comes down to support, both verbal and practical for both employer and employee with autism”

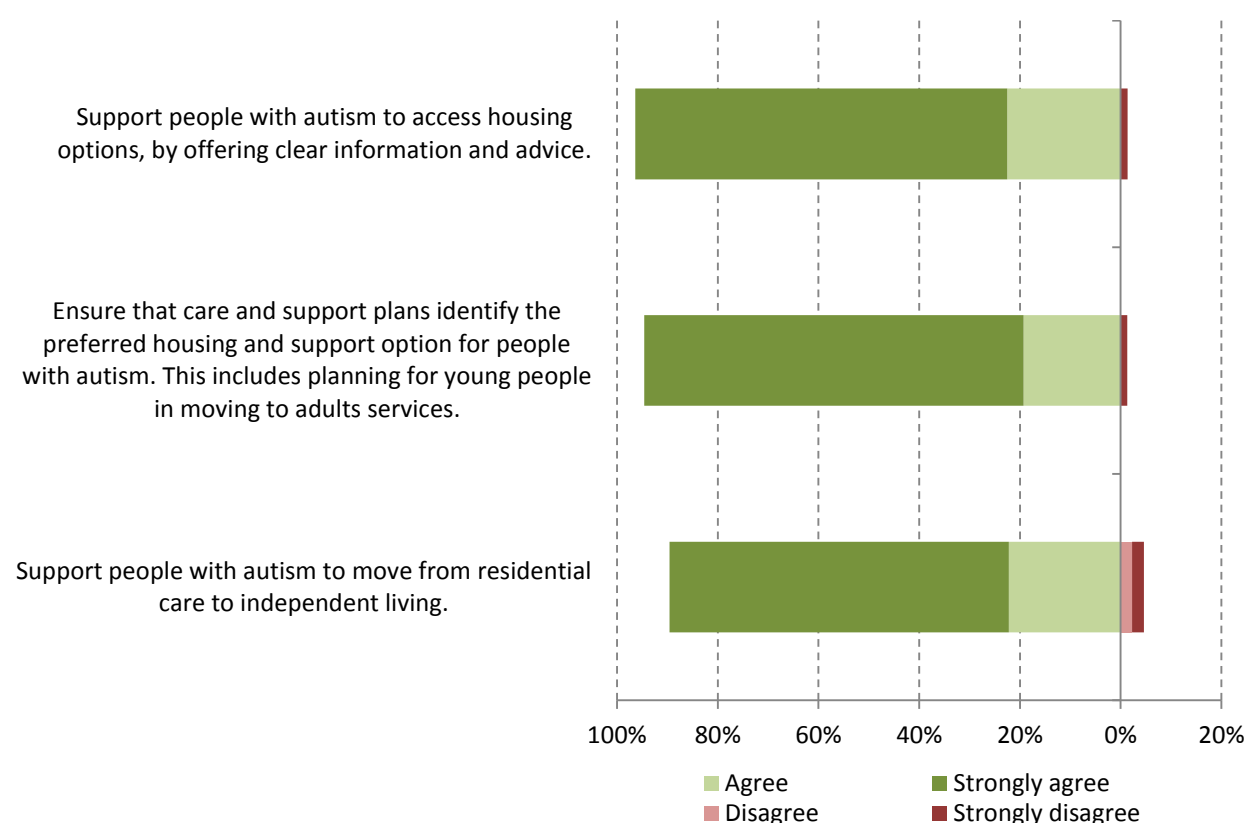
“The current provision of support is not working - people are offered support and given inappropriate support that worsens their situation. The people supporting them do not have an understanding of autism without a learning disability, and this leads them to make judgements about people and the reasons for their actions. People on the autism spectrum make fantastic employees, and this needs to be shown. The difficulty for people providing supportive employment schemes is that they cannot get support from health professionals to provide them with advice and guidance on how to work with people effectively.”

## Section 1.8 – Housing

Exercising choice and control over where and with whom we live is a fundamental part of life and independence for most people.

Respondents were asked how strongly they agreed or disagreed with a number of statements about housing, Figure 8 shows the results. There were very high levels of agreement with all of the statements in this section of the survey, although 5% of respondents disagreed that people with autism should be supported to move from residential care to independent living.

**Figure 8: Agreement with statements about housing**



Respondents were also asked if there was anything else they wanted to mention about housing services, the table below displays the most common themes mentioned by respondents. Of the 68 comments in this section of the questionnaire, 23 commented that there should be more support, specifically for those families that continue to care for someone with autism. A further 18 respondents highlighted that a flexible approach should be adopted when looking at housing for individuals with autism, and that a one size fits all approach doesn't work. There were also nine respondents who stated that more accessible information needs to be made available on housing.

Theme / Issue	No. of comments
Support for families who continue to care for individuals with autism	23
Flexible approach to housing	18
More accessible information	9
Early planning / transitional planning	6
More awareness raising of autism with housing support	6
Need to ensure the safety and security of people with autism	6
Money management support	4

“Do more when kids are younger so that they will have better life skills and not need such high levels of support when they are older.”

“It is vital that individuals and families feel that there is a range of options available to them and that time is spent early on to plan for a day when that person might leave home or move into independent living. There must be good support options which offer holistic support to meet that individual’s needs and choices including access to transport.”

“Support aging parents to feel confident their child / adult will find a safe and supportive environment to live in. Life as an adult for their child with autism I think is possibly the gravest concern for many parents of disabled children, particularly with recent exposure of care home disasters. Open up care homes, make them visible, run visitors days and events, make these places accessible but safe and sound. Pay staff more, to recognise dedicated workers in this field. Don't overly encourage personal responsibility for their own housing if the autistic person is not up to it.”

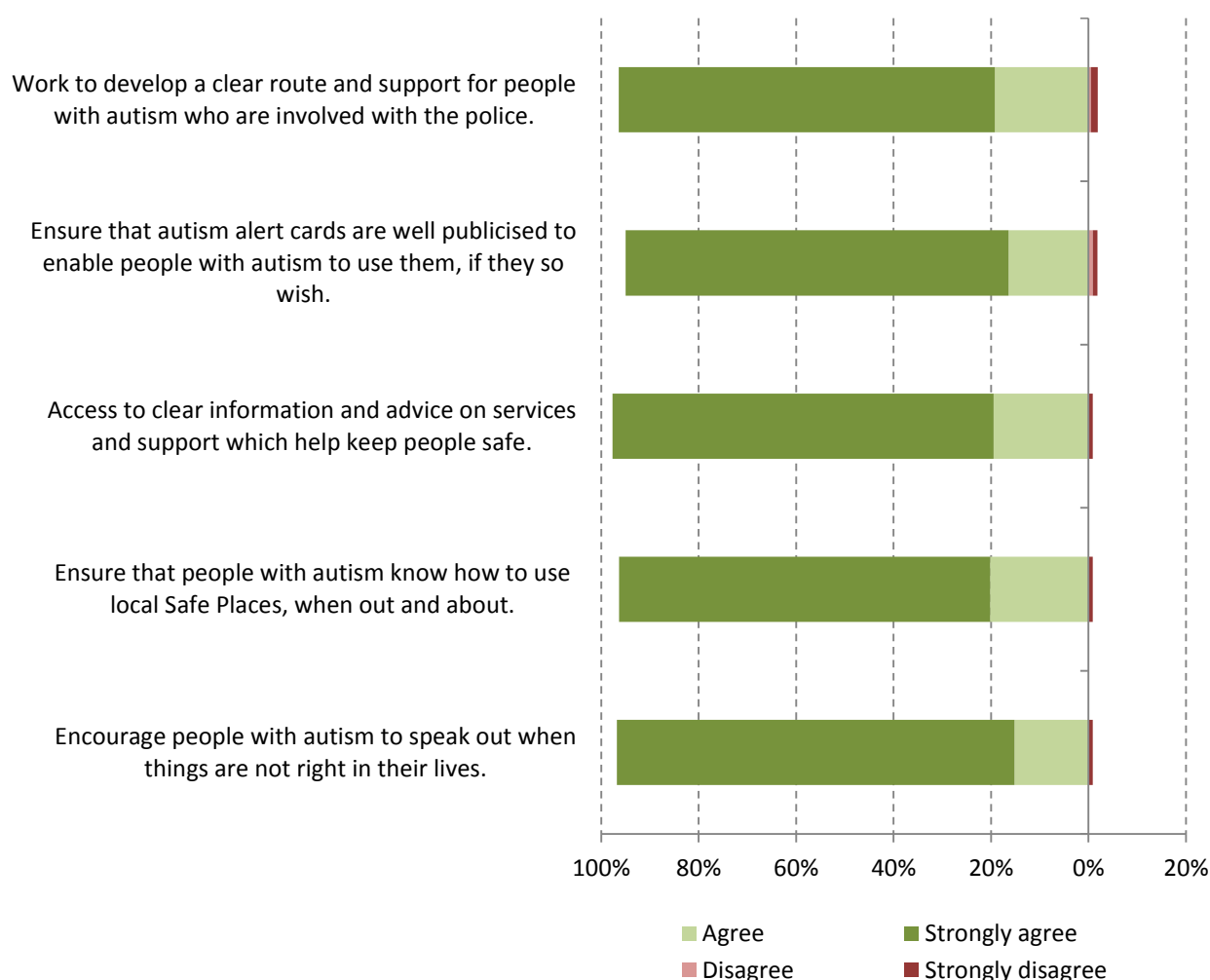
“This subject depends entirely on the potential for someone to live independently; many people on the spectrum will remain with family or in some other type of care facility. Obviously should a person be able to live independently with/without some support then they should have all suitable options given to them and any support they need to allow this to happen.”

## Section 1.9 – Keeping Safe

The challenges of social interaction can for some people with autism make them vulnerable to being a victim of crime or exploitation. People with autism have the right to live in safety and be free from hate crime, discrimination and abuse.

Respondents were asked how strongly they agreed or disagreed with a number of statements about keeping safe, Figure 9 shows the results. There were very high levels of agreement with all of the statements in the keeping safe section of the survey, with approximately only 1% of respondents disagreeing with any of the statements.

**Figure 9: Agreement with statements about keeping safe**



Respondents were also asked if there was anything else they wanted to mention about keeping safe, the table below displays the most common themes mentioned by respondents. Of the 68 comments in this section of the questionnaire, 21 commented that there should be more

awareness training, particularly for the emergency services. A further 19 respondents requested that further information was available and publicity conducted on staying safe, whilst eleven respondents mentioned that it was imperative that individuals with autism are placed in a safe environment.

Theme / Issue	No. of comments
Autism awareness training, especially for emergency staff	21
Information / publicity about staying safe	19
Placed in a safe environment	11
Support in the community	8
Autism alert cards	6
More education about autism in schools	3

“As you may have seen in the rugby advertiser there was a letter in about a horrible experience of an autism mother getting verbally abused and threatened in the town centre as she dealt with her child's meltdown and this was near a supposed safe space and the rugby rangers did NOTHING. You must, must, must train all public services providers about autism. Your emergency services need training but so do your not quite so front line services - rangers, park rangers, council workers.”

“The alert card and safe places are brilliant ideas - but I've never heard of them before today - they need more publicity”

“There needs to be a specific focus on keeping safe which starts at school. Autistic women and girls are particularly vulnerable in society. We need to provide on-going specialist support and information for this group of people.”

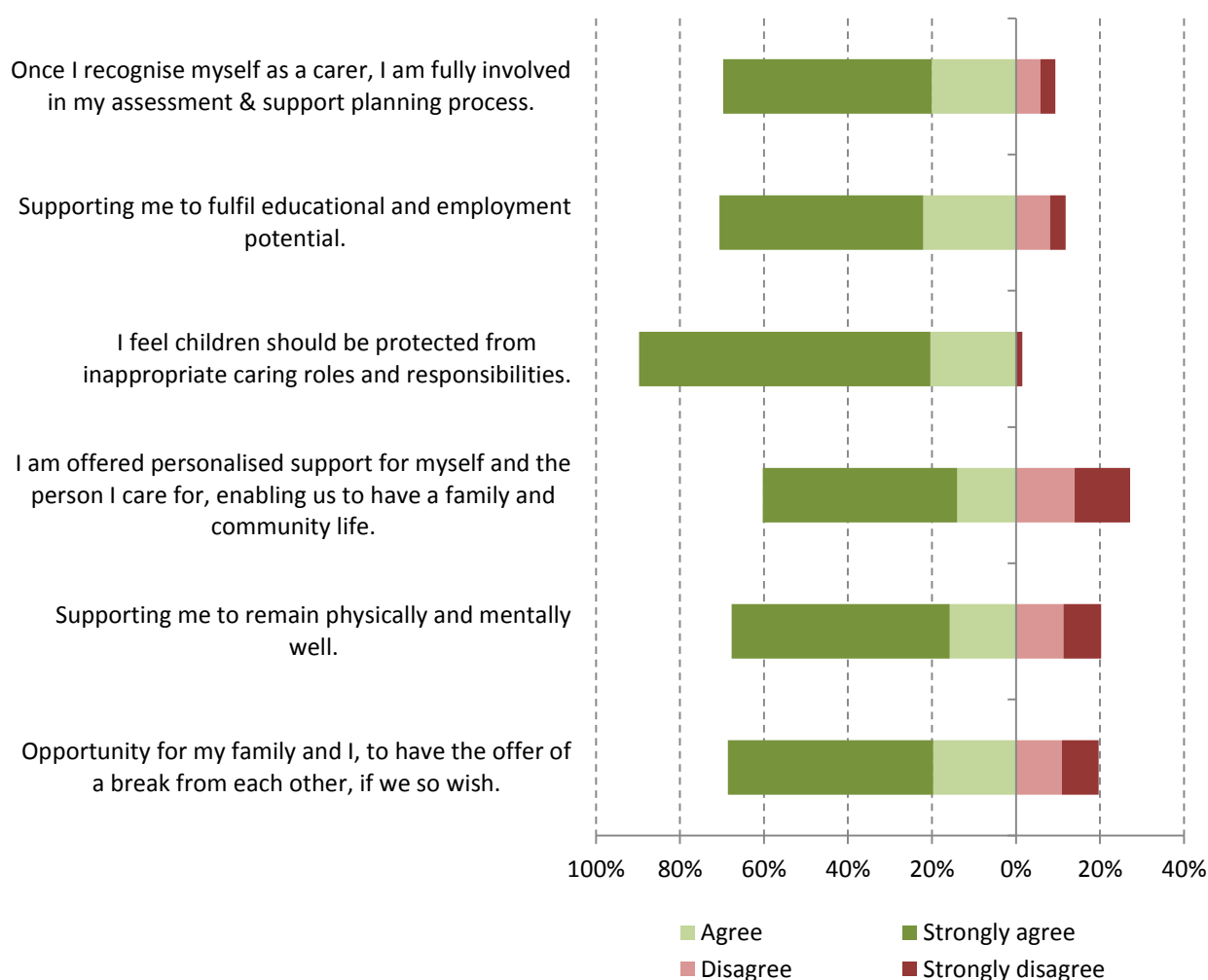
“This is genuinely the first I've heard about the "Safe Places". I've also never had any relative, doctor or other person talk about or suggest an "Attention Card" to me, throughout the last few years (though I have heard of them). Again, general awareness. Not much point having such schemes if even local autistic people or their families, your main targets, don't know about them!”

## Section 1.10 – Carers

Carers make a significant contribution to the lives of the people that they care for and to society as a whole. Through Warwickshire’s Carers Strategy, there is a strong commitment to ensure that carers are recognised, valued and supported, by helping adults and children who live and care in Warwickshire to improve their quality of life, health and wellbeing.

This section of the survey was targeted at carers of people with autism; they were asked how important a number of issues were for them by agreeing and disagreeing to the following statements, Figure 10 shows the results. The results from this section revealed slightly more mixed opinions, for example 31% of respondents disagreed that it is important they are offered personalised support for themselves and the person they care for. Statements about the opportunity for carers to have a break and supporting carers to remain physically and mentally well also received relatively mixed results.

**Figure 10: Agreement with statements about being a carer**



Respondents were also asked if there was anything else that could be done to help them in their caring role; the table below displays the most common themes mentioned by respondents. Of the 78 comments in this section, the majority of respondents mentioned something about having more support from authorities, the types of support requested were typically issues that have already been covered in previous sections of this report. Other themes from carers included more respite care, more information on caring for someone with autism and further information about how to request a carers assessment.

Theme / Issue	No. of comments
Generally need more support	40
Respite care	12
Need more information on being a carer for someone with autism	11
Details about how to get a carers assessment	9
Being listened to by authorities	7
Access to a support network	6
Access to a keyworker	5
Financial support	4

“A broader and more in depth knowledge in society about Autism. Less judgement about parenting skills, more understanding and co-operation. A recognition of the task involved in raising/caring for a person with Autism.”

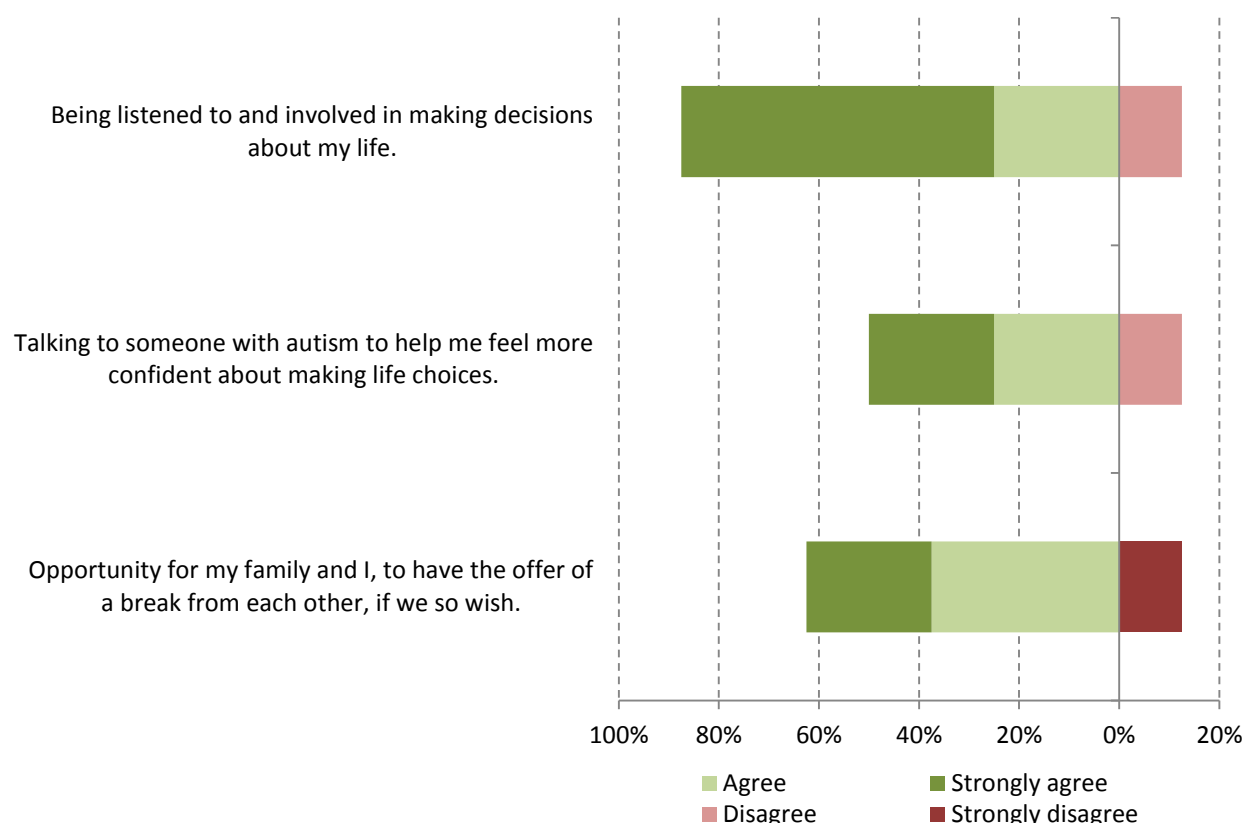
“I have never been offered a carers assessment. I do not receive adequate short breaks. I am currently unable to work due to my caring and the stress caused by this. I do not feel adequately supported or know where I would turn for support.”

“We need individualised support that meets need. The system needs to listen and take into account the views of parent and carers. All too often professionals try to tell us what we want without listening, usually because it ticks a box for their monitoring, is affordable, is what has always been done. The assumption is often that I do not have a brain and do not have the ability to make reasoned, rational decisions. Being a parent of a child with high needs means that you continually hit your head against a brick wall because managers, too often, do not have the ability to think outside the box. The best outcomes occur when people work with us, listen, do not have a fixed agenda and are solution led...”

## Section 1.11 – Having family support

This section of the survey was targeted at people with autism who receive care and support from a family / parent carers of people with autism; they were asked how important a number of issues were for them by agreeing and disagreeing to the following statements, Figure 11 shows the results. The results from this section are based on only eight responses, so should be treated with caution when interpreting them.

**Figure 11: Agreement with statements about having family support**



Individuals with autism were also asked if there were any other comments they wanted to make about receiving care and support from a family / parent carer; just four comments were received.

“Talking to someone with autism to help me feel more confident about making life choices.” As I've written, I don't know any other teens or young adults with autism/Aspergers around here, and it's crazy trying to search and navigate local newspapers and websites trying to locate a specialised group/club. So, I'm afraid I don't know what to answer for that question. Plus school bullying has put me off the idea of approaching most stranger-teens for life, anyway!”



## Section 1.12 – Anything else

Finally, the adult’s questionnaire asked respondents if there was anything else they felt should be included in the strategy. Many respondents took the opportunity to re-emphasise a previous point, so the comments in this section (87 in total) provide a good summary of the issues raised in previous sections of the questionnaire.

Theme / Issue	No. of comments
Better support for families / people with autism	28
Greater understanding and awareness	10
Easy access to information about autism	9
Don’t cut funding to services	8
Transparent assessment process	7
Involve and listen to carer and individuals with autism	6
Early planning / Transition planning	5
Training for professionals / carers	5
Better support networks	4
Communication updates	4
Professional Autism network / lead	4
The importance of a safe and secure environment	4
Respite care	2

## Section 2 – Children and Young Peoples Survey

This section of the survey presents the findings from the Children and Young Peoples Autism Survey, in total 75 responses were received to this questionnaire. It was clear that not all respondents to the questionnaire were children, many were completed by adults responding on their child's behalf.

### Section 2.1 – Autism Definition

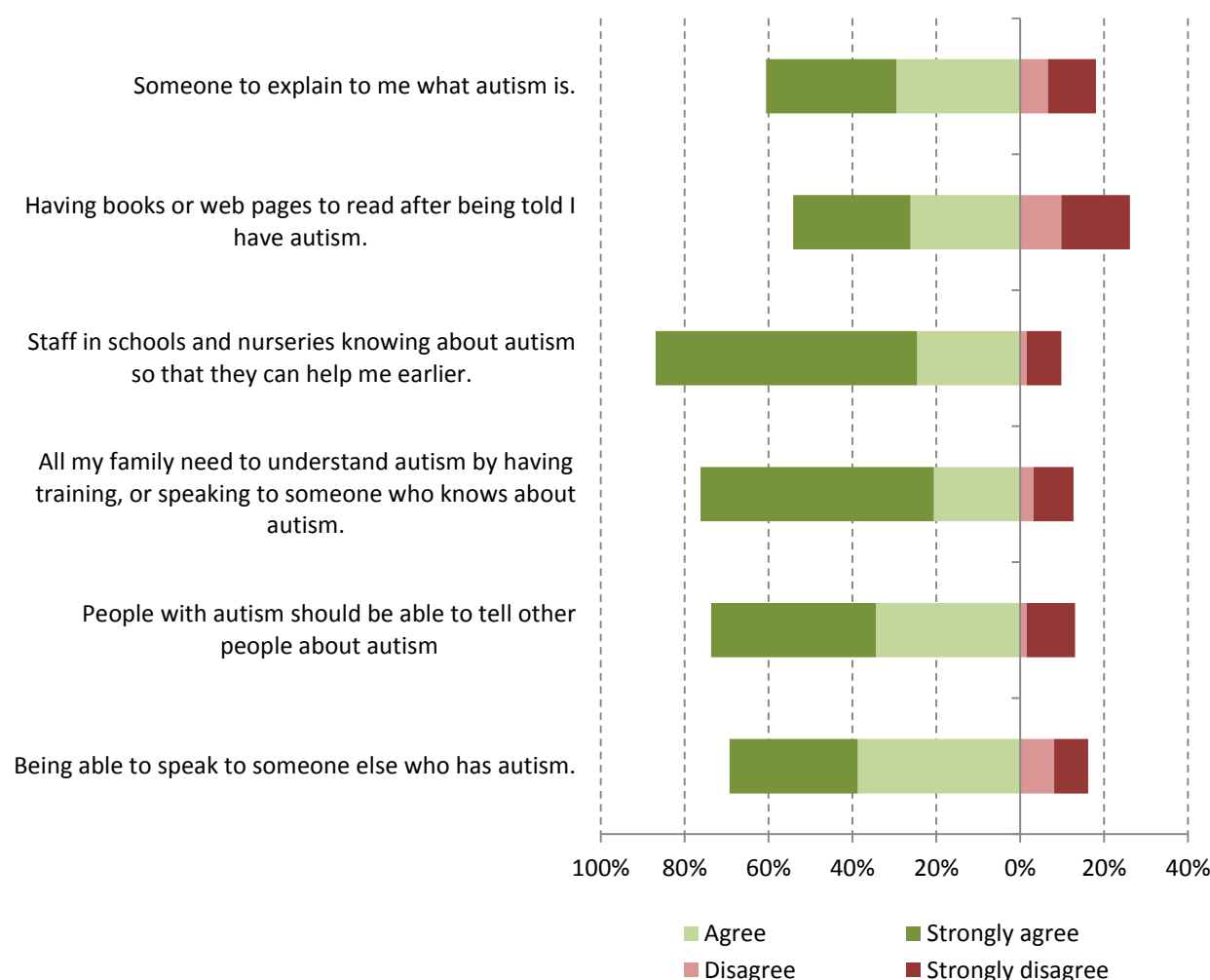
Firstly, respondents to the survey were asked what they think autism is. Over 70 young people responded to this question, their responses are summarised in the table below. The most frequent responses involved reference to difficulties communicating and a lack of social skills, but another popular response involved thinking, acting and learning in a different way to their peers.

Theme / Issue	No. of comments
Difficulties in communicating	20
A lack of social skills	20
Learning / acting / thinking in a different way	17
A disability or learning disability	13
Not liking change / Having a specific routine	9
Sensory disorder	8
A lifelong condition	8
A spectrum disorder / degrees of severity	6
A disorder of the brain	5
Problems with imagination	4
Easy to get upset and angry	3
Can be a positive condition	2
Above average intelligence	2
Fidget and inability to keep still	2

## Section 2.2 – Finding out about my Autism

Respondents were asked how strongly they agreed or disagreed with a number of statements on finding out about autism, Figure 12 shows the results. The majority of respondents agreed with each of the statements below, however there were significant levels of disagreement with some of the statements. Just over one-quarter of respondents (26%) disagreed with having books and webpages to read following being told, whilst nearly one in five respondents (18%) disagreed that they needed someone to explain what autism is to them.

**Figure 12: Agreement with statements about finding out about my autism**



Young people were also asked to make any comments about any other issues relating to finding out about autism, just over 20 comments were made, and the most popular themes are shown in the table below. Comments about having easy access to useful information and better public awareness and understanding of the condition were cited most frequently.

Theme / Issue	No. of comments
Easily accessible information	5
Greater awareness and understanding in society	5
More support from authorities	4
Talk to other young people with autism	3
One to one support from a professional	1
Earlier diagnosis	1
Central information point	1

“Being able to talk to other children who have autism and knowing I am not alone.”

“Helping my siblings to understand and cope with my condition. Assistance in gaining my statement of special needs for schooling.”

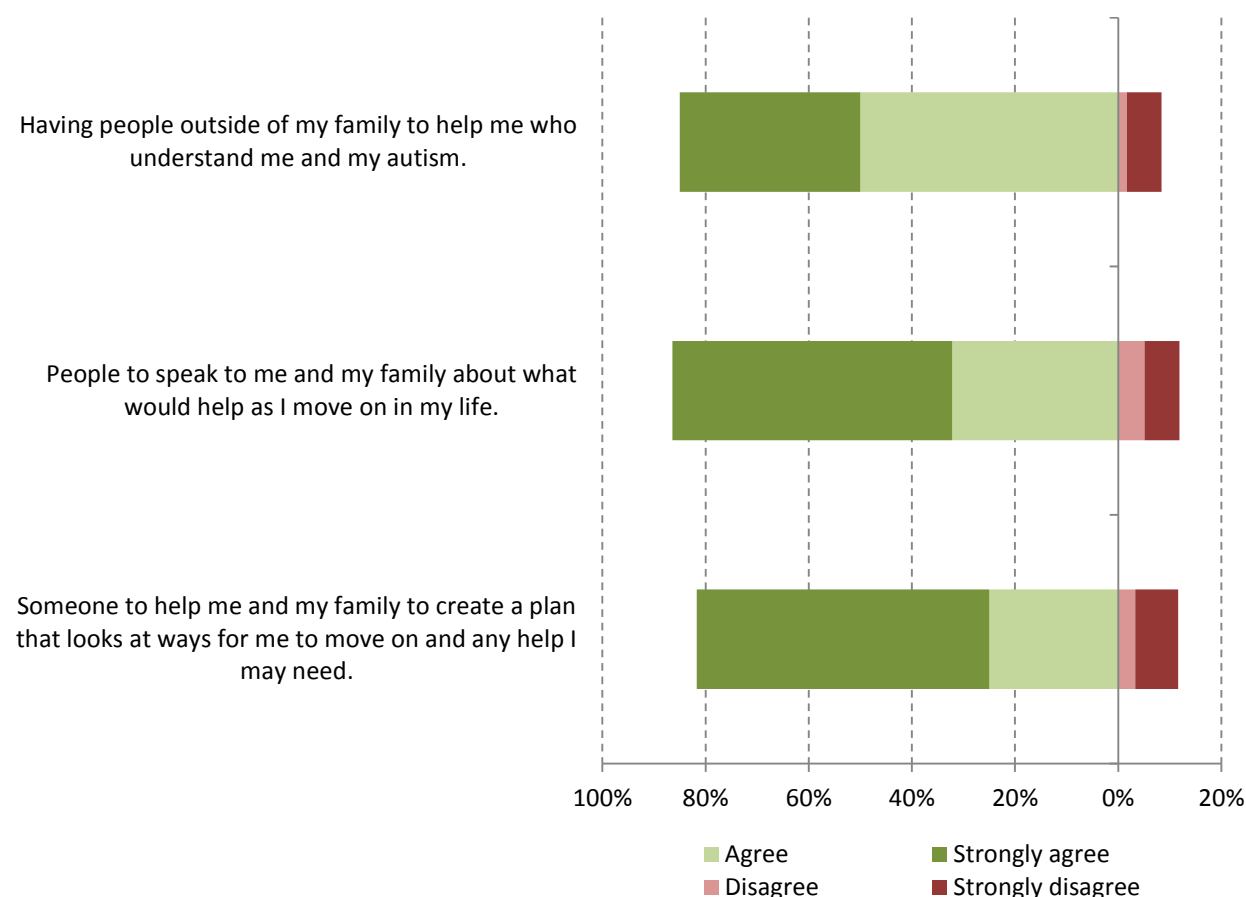
“Our son was not diagnosed with ASD until the age of 10. We always knew something was wrong but found it extremely difficult to find somebody to help us. We consulted a child paediatrician at Warwick hospital - and eventually were referred to CAHMS who diagnosed our son within an hour. I feel that if we had diagnosis earlier things would have been so much better for our son - and we would have implemented coping strategies etc. at a much earlier age - instead of attributing his problems down to bad behaviour.”

“There is a wealth of information about autism for parents on the internet however if you do not have access to this information you are truly in the dark. I think health professionals opinion regarding autism is very negative and nearly all the health professionals I have come across appear to believe there is not much you can do to help your child and to just cope as best as you can. I feel this breeds depression and desperation in parents and feel it would be much better if parents were encouraged to help their children with their difficulties and shown how to do this. This I believe would give parents a better sense of control and would enable them to feel positive about parenting their child and be more positive about the future. Although it is very sad and upsetting to find out that your child has these difficulties it does not have to be given as a diagnosis for you all to have a miserable life, it is simply not true. I think counselling should be offered to parents to help them adjust and accept the diagnosis and move on with their lives in a positive way with their children.”

## Section 2.3 – Moving on in my life

Respondents were asked how strongly they agreed or disagreed with a number of statements about moving on in their life, Figure 13 shows the results. The large majority of respondents agreed with each of the statements in this section, with levels of agreement in excess of 80%.

**Figure 13: Agreement with statements about finding out about my autism**



Young people were also asked to make any comments about any other issues relating to moving on in their life, less than 20 comments were made, the most popular themes are shown in the table below. Comments about being more aware of what help and information is available were most frequently cited, as well as actually receiving that support.

Theme / Issue	No. of comments
Need to more about what help and information is available	4
Generally need more support	2
Family led networks	1
Better transition planning	1
Having care plans in place	1

“Care plans need to be in place for children and adults. The main concern of all parents is nearly always what will happen to their child, or grown up child with autism when they are no longer there to take care of them. Facilities to cater for their needs are few and far between, most are inappropriate and we know are run by unqualified health care workers with little understanding of ASD. It is also clear that these facilities are not closely monitored enough and as parents we feel our children/adults with autism are not safe in these environments. This issue needs to be addressed. Care in the community is important to me, I don't want my child locked away as an adult because he is not considered to behave in a normal manner, it is not a crime to be autistic.”

“I think there is lots of support in education and initially after diagnosis, but any other support seems to be for the severely Autistic, not for parents of children who are only mildly on the spectrum. Also there is no support that I have been told about, to support my child in after school activities, i.e. swimming, sporting activities, drama groups etc. unless it's at school.”

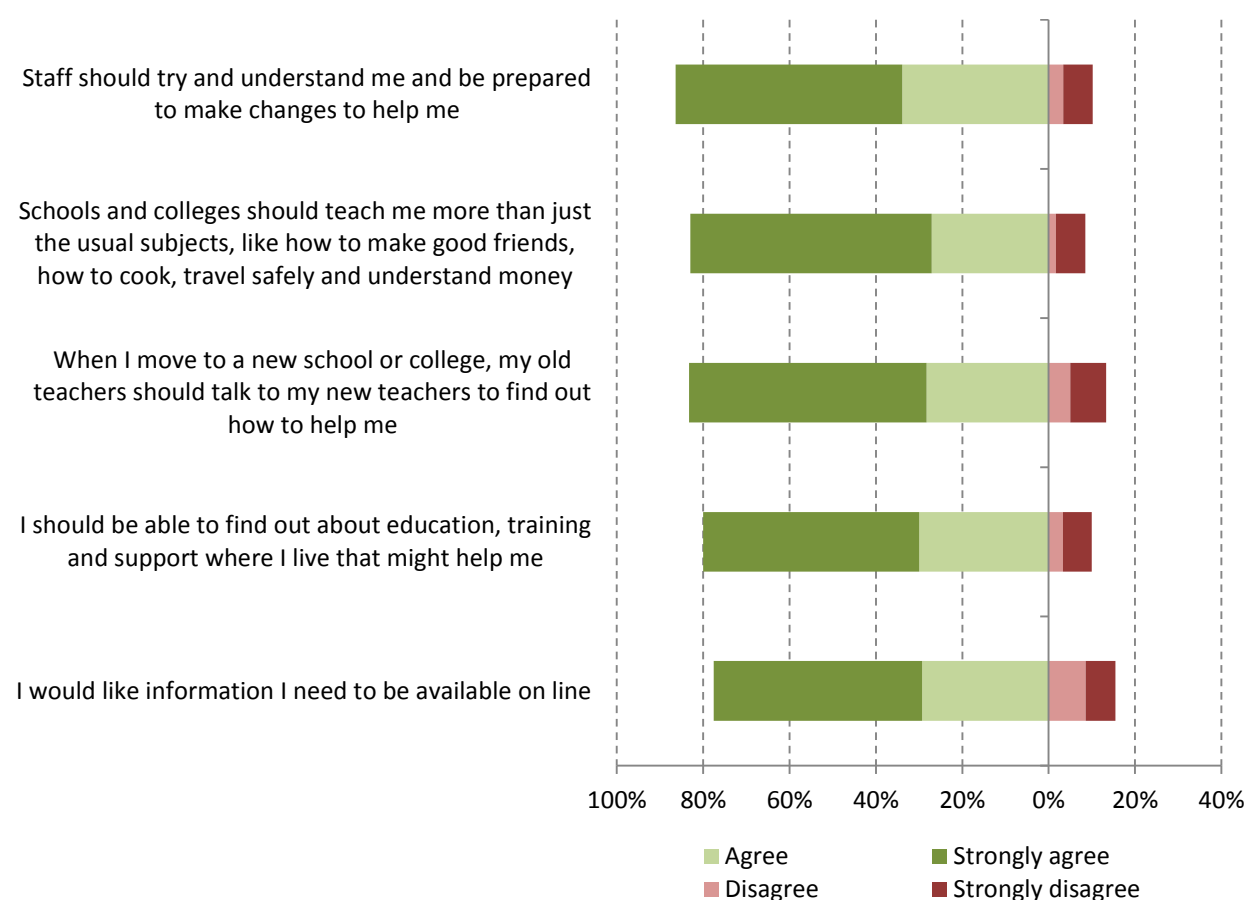
“Moving from primary to secondary school was difficult as no friends moved with me. It would have been easier if I could have visited my new school with a member of staff that knew me already from primary.

“We have had no help or advice since both our sons have been diagnosed with ASD. We have struggled to come to terms with it and feel that every day is a battle with the boys. It would help if schools were more informed and willing to help. We are well aware that our son is not going to cope when he goes to high school but his current school do not want to help. They don't understand his anxiety and the struggle we have to get him to school when he is worried.”

## Section 2.3 – Schools and Colleges

Respondents were asked how strongly they agreed or disagreed with a number of statements on Schools and Colleges, Figure 14 shows the results. Again, the majority of respondents agreed with each of the statements in this section, with levels of agreement at approximately 80%. However, one in six respondents (16%) disagreed that they would like information to be available on-line.

**Figure 14: Agreement with statements about finding out about my autism**



Young people were also asked to make any comments about anything else that would help them with School or College life. The most popular theme to emerge from the comments was a greater awareness and understanding of autism by other pupils in schools and colleges. Respondents felt they also needed more help with social and life skills as well as addressing any bullying that individuals with autism are subjected to.

Theme / Issue	No. of comments
More awareness and understanding of autism	5
Help with social / life skills	3
Address issues with bullying	3
Better trained teachers to support students	2
Generally more support at school	2
Taster days when moving schools / moving to a different class	1
Buddying / Mentoring scheme	1

“A social club for individuals with autism to help me make friends and develop my social skills.”

“More awareness of autism is definitely required in mainstream schools. I hear many stories of children who are bullied by the other children who do not understand their condition. It also appears that teaching staff do not fully appreciate that autism is a medical condition and not a child behaving badly or being difficult. Children who are able to attend mainstream school with an autistic spectrum disorder, with the right help, should be able to integrate and have a positive attitude towards them, this starts with teaching staff. At the moment I feel that in mainstream schools children who are on the ASD spectrum are feeling very socially isolated, and I believe this is causing a detrimental effect on the ASD which will undoubtedly cause society as a whole greater problems in the long run in time and investment is not made to correct this situation.”

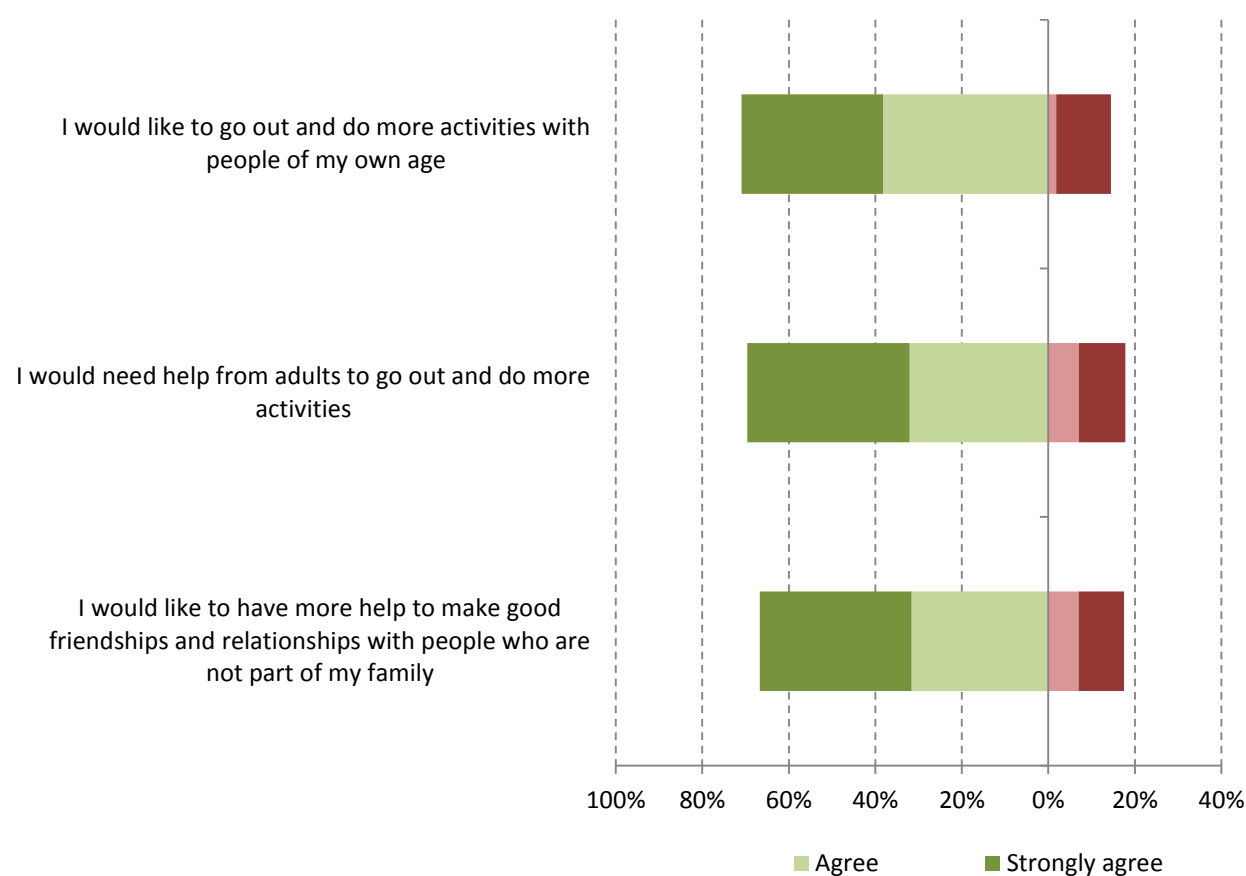
“Our son's secondary school has been excellent at providing extra support and care. The first year was very difficult as a lot of bullying went on - other children didn't understand our son - and he has had to be "taught" social skills. Academically he struggles - due to his autism and dyslexia. The school have provided a notebook for him to type his work into.”



## Section 2.4 – Activities outside my home

Respondents were asked how strongly they agreed or disagreed with a number of statements on activities outside their home, Figure 15 shows the results. Approximately 70% of respondents to these questions agreed with each of the statements, slightly lower than in the previous two sections. Nearly 20% of respondents disagreed with each statement, with the remaining respondents not committing to a response either way.

**Figure 15: Agreement with statements about activities outside the home**



Respondents were also asked what they would do if they were out with friends, their parents weren't with them and they felt afraid. In this situation, the most frequent response was for children to phone a member of their family for help, usually a parent. However, for many respondents, they would never find themselves in this scenario in the first place, due to never going without their close family. Other responses included contacting the emergency services, getting help from a shop assistant or become distressed or angry.

Theme / Issue	No. of comments
Phone family for help, usually their Mum	9
Wouldn't be in this situation in the first place	5
Contact a shop assistant / other official	3
Contact the emergency services	3
Don't know	3
Try to play and talk to friends in question	2
Go back home alone	2
Become distressed and angry	2

“Call my parents to come and collect me.”

“I'd be afraid and panicking, this would never happen to me because I don't want to go out and about.”

“My sons will not go or do anything without us. Going anywhere is a complete nightmare. It would be good if help could be provided to talk to and encourage autistic children to do activities specifically for them.”

“Talk to a police office or member of staff in shopping centre.”

## Section 2.4 – Anything else

Finally, respondents were asked if there was anything else that would help them. The main themes are shown in the table below, and again highlight the key issues that young people had previously mentioned in the questionnaire.

Theme / Issue	No. of comments
Better awareness and understanding of autism	5
Better training and information available for parents / carers	4
Easier access to social activities / hobbies	3
Autism can be very isolating	2
There are positives, and these should be highlighted / celebrated	2
Generally more support is required	2
Clearer diagnosis pathways	1
Listen to child / family more	1
More respite care available	1
Courses on social skills	1

## Section 3 – Respondent profile

### Adult's Survey

Characteristic		No. of responses
Gender	Male	36
	Female	174
Age Group	Under 18 years old	10
	18 – 29 years old	19
	30 – 44 years old	77
	45 – 59 years old	86
	60 – 74 years old	20
	75 years old and over	0
Disability / situation	Someone who has Autism / Asperger Syndrome	26
	Someone who has a learning disability / difficulty	12
	Someone who has a mental health problem	19
	Someone who has a physical disability	6
	Someone who has a long-standing illness	12
	Someone who has a terminal illness	0
	Someone who has sight or hearing loss	2
	A person with dementia	0
	Someone who has problems connected to ageing	1
	Someone who feels you may be misusing alcohol or drugs	0
	Someone who cares for a person with Autism / Asperger Syndrome	114
	Part of an organisation who support people with Autism / Asperger Syndrome	39

Characteristic		No. of responses
Employment status	Working full-time	31
	Working part-time	45
	Self-employed	11
	Further Education	7
	Short term unemployed	3
	Long term unemployed	26
	Full time volunteering	1
	Part time retired	12
Borough / District of residence	North Warwickshire Borough	12
	Nuneaton and Bedworth Borough	30
	Rugby Borough	24
	Stratford-on-Avon District	51
	Warwick District	66
	None of the above / Don't know	10

## Children's Survey

Characteristic		No. of
Gender	Male	39
	Female	17
Age	6 - 10 years old	17
	11 - 16 years old	34
Disability / situation	Someone who has Autism / Asperger Syndrome	43
	Someone who has a learning disability / difficulty	19
	Someone who has a mental health problem	2
	Someone who has a physical disability	2
	Someone who has a long-standing illness	7
	Someone who has a terminal illness	0
	Someone who has sight or hearing loss	0
	Someone who cares for a person with Autism / Asperger Syndrome	10
Borough / District of residence	North Warwickshire Borough	6
	Nuneaton and Bedworth Borough	3
	Rugby Borough	7
	Stratford-on-Avon District	11
	Warwick District	22
	None of the above / Don't know	5