

Presented to the 3<sup>rd</sup> February 2014 meeting of the Autism Programme Board

# **The Adult Autism Strategy Review Online Survey Analysis**

**September 2013**

## ***Introduction & Background to the research***

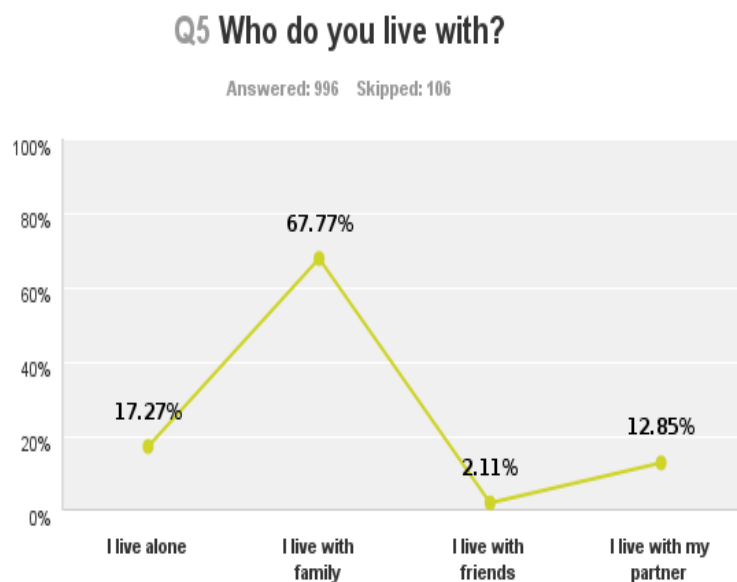
Autism Plus in partnership with the Hidden Impairment National Group conducted an online survey for adults with autism and their parents and carers to identify the impact the 2010 Adult Autism Strategy has had on individuals locally. The survey was publicised nationally and captured information on all aspects of the strategy including, education, housing, employment, awareness raising and training as well as transition. We were keen to capture real experiences and provide case studies of good practice examples of support individuals received whilst reporting on changes that still have a need for improvement locally and nationally.

The survey captured the experiences of 1102 individuals nationally, with 363 this being 33% of these being individuals on the autism spectrum and 67% parents/ carers or individuals representing the views and experiences of those with autism directly.

The survey captured age groups of individuals, and clearly showed that the majority of those completing the survey were young adults or representing young adults. Age categories and respondents from each group are as below.

54% of respondents were themselves or representing individuals between the ages of 18 and 34; 36% of respondents were themselves or representing individuals between the ages of 35 and 54; with the remaining 10% being 55 were themselves or representing individuals from this age group.

The survey sought to capture the home situations of individuals responding in order to ascertain how individuals circumstances may be affected by different questions asked. The table below highlights where respondents were living at the time of the survey.



Over 85% of respondents either live alone or with their family. The table below gives additional information where people specified that they lived with a service provider by type of service.

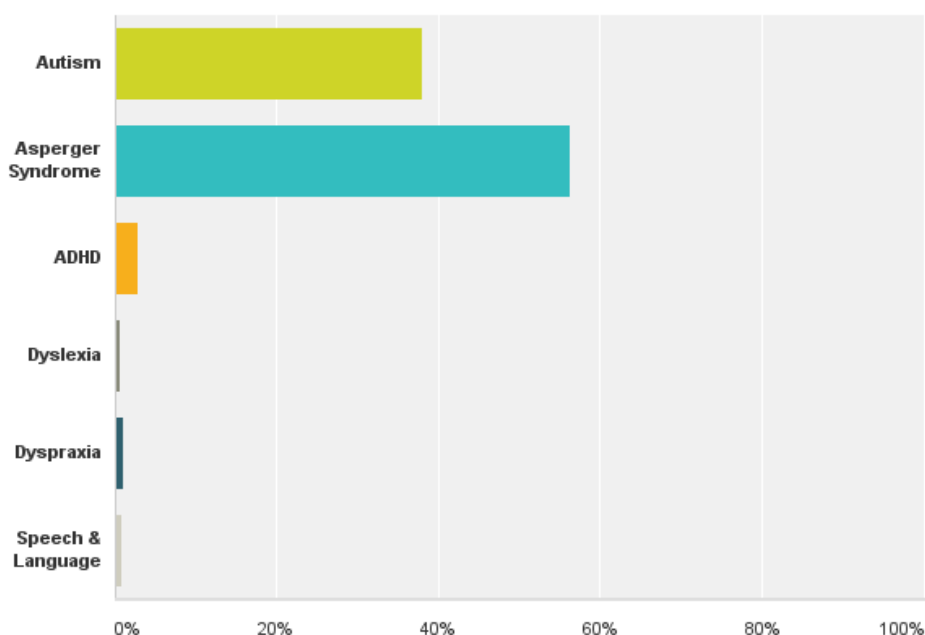
Type of Service	Total Number of Respondents	Percentage of No. who Answered
Supported Living	29	2.9
Residential Service	23	2.2
Other	4	0.4

### ***Diagnosis***

The survey and analysis acknowledges that the National Autism Strategy impacts on many other conditions, not just those individuals diagnosis with autism specifically. In light of this we sought to capture information from respondents with associated conditions that the National Autism Strategy could potentially have an impact on. We were also keen to capture experiences of those that did not have a formal diagnosis but considered themselves to have an autism spectrum condition. This section highlights the respondents, diagnosed and associated conditions of those that responded to the survey.

72% of respondents did have a formal diagnosis, broken down below into other associated conditions with 56% of respondents having a diagnosis of Asperger Syndrome (a form of autism) through to 1% of respondents having a diagnosis of speech & language impairments.

#### **Q7 If yes, please select your diagnosis from the list below**



We also captured data on individuals with a dual diagnosis, with 51% of respondents with a diagnosis highlighting a second diagnosis alongside this. Most common secondary diagnosed being; learning disability, anxiety related disorders, Attention Deficit Hyperactivity Disorder, Obsessive Compulsive Disorder and Epilepsy.

It was important to note that whilst not all respondents had a diagnosis, many of those responding did consider themselves to have an autism spectrum condition. The table below highlights out of 974 people responding to this question the numbers who considered themselves to have a related condition. Whilst only 72% of those responding to the full survey had a full diagnosis, this section highlights that 974 out of 1102 (88%) of respondents considered themselves to have an autism spectrum condition.

<b>I consider myself to have autism</b>	<b>56%</b>
<b>I consider myself to have ADHD</b>	<b>6%</b>
<b>I consider myself to have Dyslexia</b>	<b>4%</b>
<b>I consider myself to have Dyspraxia</b>	<b>7%</b>
<b>I consider myself to have Dyscalculia</b>	<b>1%</b>
<b>I consider myself to have difficulties related to anxiety</b>	<b>26%</b>

Many individuals responding noted specific difficulties and concerns around their diagnosis, some of the statements made are shown below;

“Having both Aspergers and ADHD I have the worst of both worlds. I am impulsive and make decisions without forethought on the one hand and am so rigid that I cannot shift away from them even if demonstrably inappropriate or self-defeating.”

“You do not have to be diagnosed to either have problems or need help. Other people always seem to need a 'label' before they appreciate you have problems.”

“It has taken me a long time to understand and recognise that I have more than one condition. I do not like talking about it and get very distressed, but am realising as I get older that I have different thresholds and abilities/disabilities to people I meet. I do not like being different.”

These statements highlight the comments of many of the respondents. Some of whom felt the dual diagnosis gave them multiple barriers, others who did not like the notion of a label, and many who found it hard to consider themselves to have multiple difficulties.

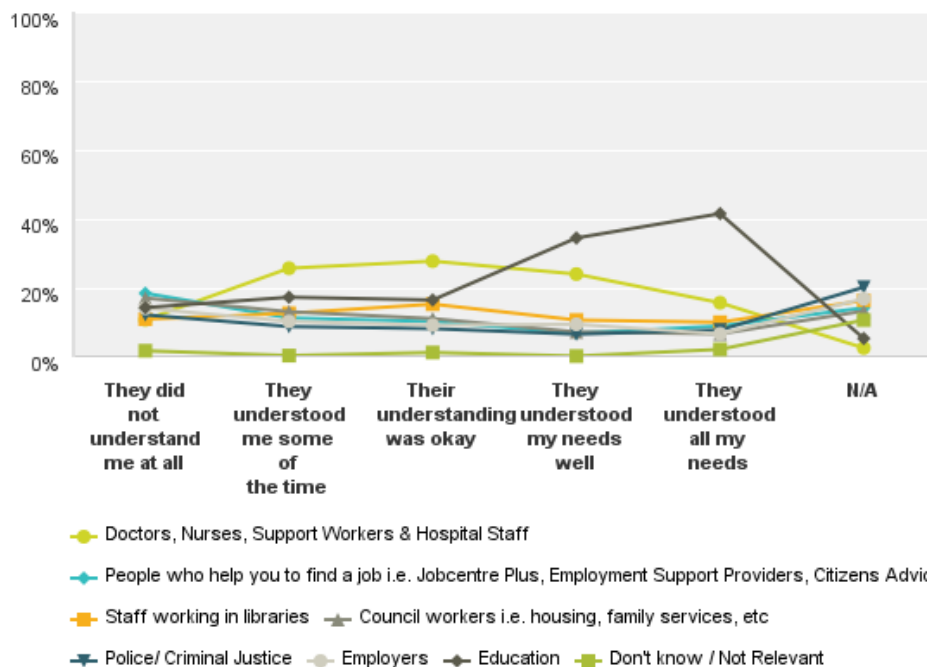
### ***Understanding & Knowing about your Autism***

We asked individuals with autism to rate the level of understanding of various service providers.

The data in the chart below shows that understanding within education is much higher than other service provisions, particularly when moving into adult services. Respondents suggested providers that understood all their needs dropped from 42% in education down to 7% in employment provisions. There was a greater understanding in healthcare services generally and least understanding from employers and criminal justice services. Library staff understanding tended to be spread out quite evenly across the board for understanding, as did council workers, showing lack of consistency in awareness across these provisions.

## Q12 How would you rate the level of understanding of your condition of the following service providers?

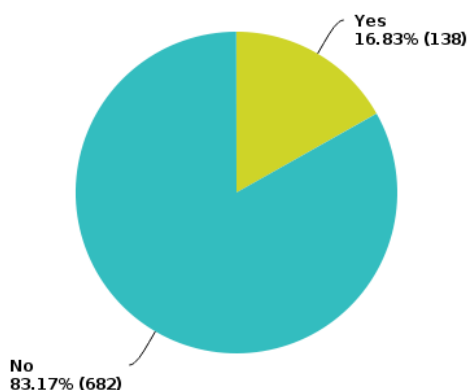
Answered: 826 Skipped: 276



We asked respondents to let us know if they had been involved in delivering awareness training locally themselves. The responses suggest that there is a significant amount of work that still needs to be done to improve the awareness of this type of opportunity and how this is communicated to people with Autism. Currently only 16.83% of respondents have been involved in delivering local training.

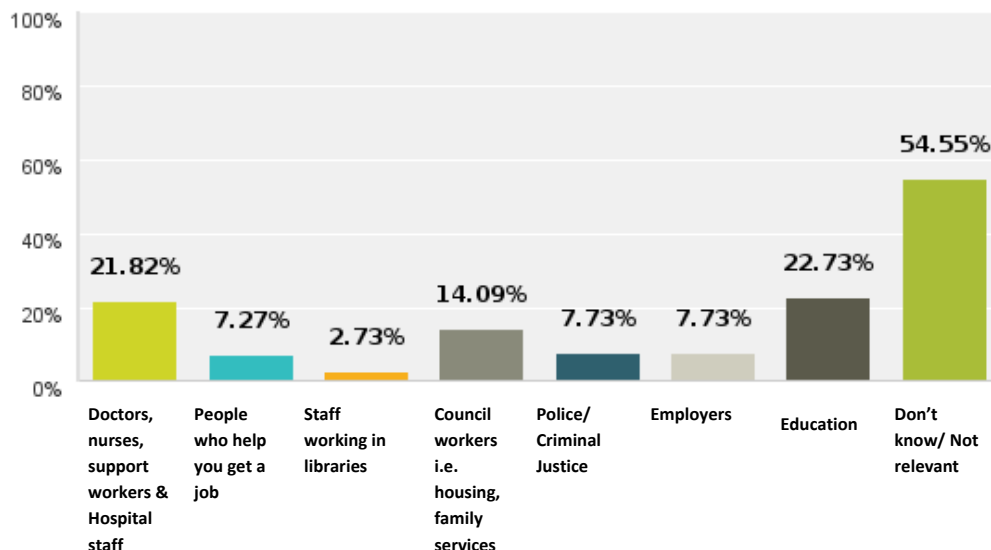
## Q13 Have you or anyone you know been invited by your local authority to be involved in delivering training and awareness of your condition in your local area?

Answered: 820 Skipped: 282



## Q14 Please select which organisations you have delivered training or awareness raising for.

Answered: 220 Skipped: 882

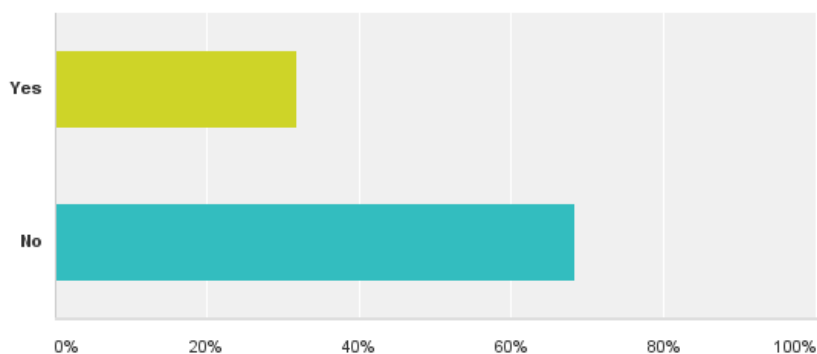


Linked to Question 13, the sample size for this question is significantly reduced due to fewer people being involved in training. It should also be noted that where the higher satisfaction rates in Question 12 are achieved is also where most of this type of training has been delivered. However, more work would need to be carried out to determine if this has a direct correlation as these professions have had more exposure to autism over the years. Figure 1 describes in more detail the breakdown of where training has been delivered.

As part of our analysis of the understanding and awareness of service provisions, 56% of responders highlighted that they have been in contact with service providers that they consider to have a good understanding of their disability.

## Q16 Have any of the everyday services that you use made adjustments that help you access their services? i.e. bus and train companies, housing, local shops, workplaces, employers, schools, colleges, etc.

Answered: 748 Skipped: 354



Whilst there is an emphasis on public sector organisations to increase awareness and understanding we were keen to also capture data on everyday services such as public transport, local shops, schools, etc that had made specific adjustments for individuals needs.

The data suggests that universal and mainstream services are not making adjustments as standard practice, however there are a high proportion of individuals reporting that reasonable adjustments are being made. There are also a number of comments to suggest that reasonable adjustments can have a significant impact on the experience received by an individual with Autism.

Out of 748 respondents to this question only 31% stated that provisions had made adjustments for them. Below are a few of the good practice examples that were highlighted by respondents.

“XXXXX College adjusted the level 2 course in Travel & Tourism to allow me to work on my own with a support worker as opposed to coming into class. The bus company has enabled me to have a free bus pass and permission for me to be accompanied by a support worker for free”

“At college I have a mentor who I can see once a week to help me with finding new class rooms and filling in forms and helping hand my work in with the correct covering sheets.”

“Some gym instructors allow me to remove my shoes towards the end of the class (accommodating sensory sensitivity)”

“Cinema - providing an isle seat. Telling me how busy it will be in advance.”

Many individuals responding noted the impact the lack of awareness their difficulties had on their lives.

“My son struggles to cope with simple day to day interactions in places such as post offices, train stations and libraries, meaning that his access to services is severely reduced. He will walk out without completing the transaction if something "goes wrong" and he is not understood.”

“I have major problems with supermarket checkout assistants who expect people to pretend to be cheerful and friendly at all the times; I can't do this”

“It is not obvious (at least to me) how one would go about requesting such adjustments, even if such adjustments are available, and even if such adjustments are supposed by law, to be made.”

“My local mental health providers do not understand my condition well and struggle to meet my mental health needs. Getting specialist advice for my condition is proving to be very difficult.”

Many others commented on the general lack of awareness and the need for more specific autism training to be made available to a wide range of organisations and not only statutory services.

### ***Finding out if you have Autism***

Of the 575 respondents that answered this section, 27% received their diagnosis after the launch of the Autism Strategy in 2010. 60% of respondents had received their diagnosis pre 2010 and a further 13% did not specify when they were diagnosed by year.

This clearly shows an increase in the rate of diagnosis received with the previous spread of diagnosis being over a 24 year span from 1986 through to 2010, an average diagnosis per year of 2.5% per year, which has increased to an average of 9% diagnosis rate of respondents over the past 3 years since the strategy was implemented.

As a focus of the strategy is on post diagnosis support it was important to capture data on what information individuals had received and if this was appropriate to their needs at the time.

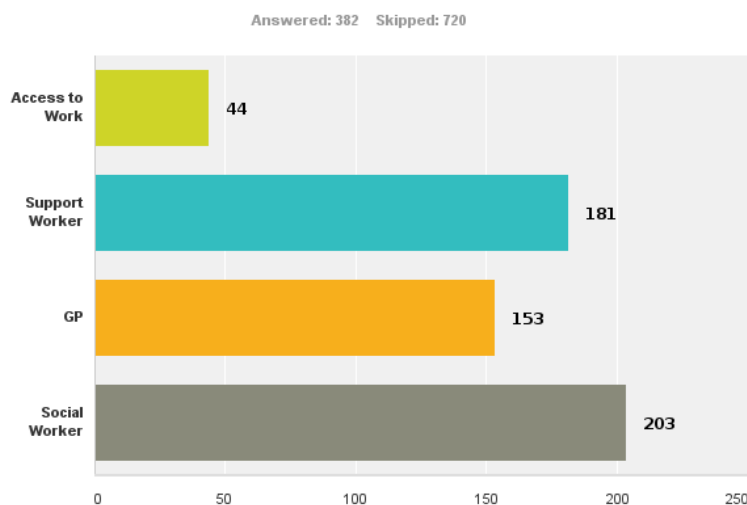
Out of 679 respondents 89% noted that they were not offered a community care assessment post on receiving their diagnosis, with 22% of those not being offered an assessment having received their diagnosis post 2010. Some reported that an assessment was not available locally unless their needs were likely to be identified as critical, others reporting they had to request an assessment, it was not automatically offered. Others reporting that they didn't receive anything post diagnosis, and didn't know where to go to ask for support/ an assessment.

When looking at post diagnosis support only 29% said they received any information at all after receiving their diagnosis. We asked those who had received further information to explain in what format this information had been received, the majority of respondents saying post diagnosis information was provided verbally. Further research would need to be done to look at the effectiveness of the information provided however as many individuals would find it difficult to remember information provided verbally where this was not followed up by written guidance.

Of those individuals that did access support post diagnosis, the majority of these received support from social workers, or support workers, with a proportion also receiving support from GPs and a small number additionally receiving support from Access to Work.



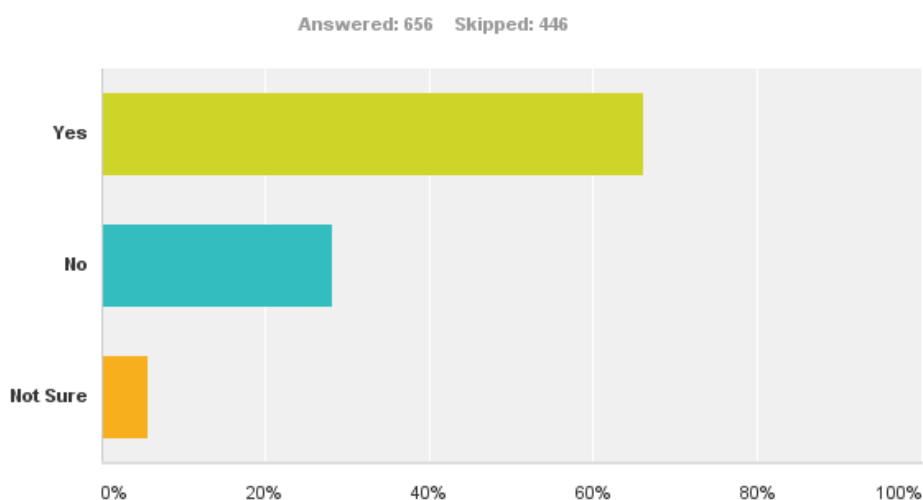
### Q23 What support have you been able to access to help with your condition?



Many individuals commented on the difficulties accessing support at all, with one respondent simply commenting “it’s difficult to access support. I’ve given up.” Another noting the struggle to get support “I had to fight for support, diagnosis to be recognised, fight for social care assessment, mental health teams didn’t want to know, social care teams didn’t want to know”

Data was captured on how involved parents/ carers were in helping plan support for individuals, with a high number of family members being engaged in planning support as shown below.

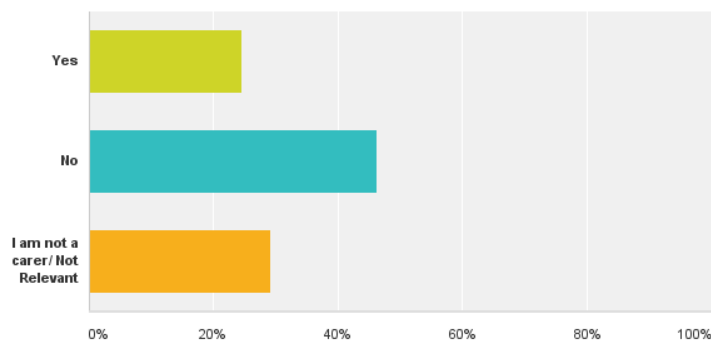
### Q24 If you have family or a partner were they involved in any discussions regarding your support?



Despite the high numbers of individuals being involved in planning support, a smaller proportion have been able to access carers allowance to support family members post diagnosis as shown in the diagram below.

**Q25 If you are a carer for someone with autism do you receive Carer's allowance?**

Answered: 679 Skipped: 423



Some comments were captured on the difficulties parents/ carers experienced when trying to support individuals with autism in accessing support.

“As a carer I was involved in discussions but not always listened too. My son comes across as a very articulate person and often says what he thinks a person wants to hear rather than reality. Social workers do not seem to grasp this fact.”

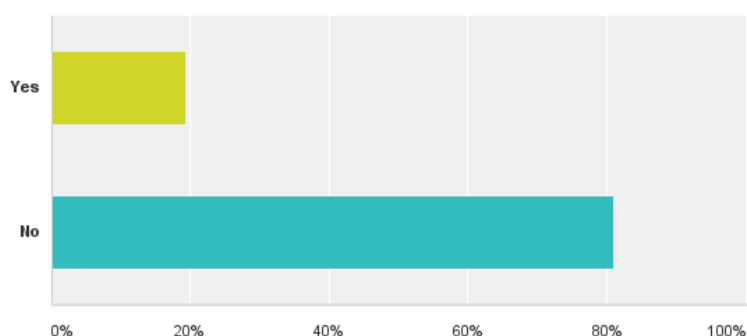
“We were only involved with any discussions regarding our son's support because our son and we insisted - but it made no difference; the Mental Health Team disregarded any of our input and concerns.”

It was apparent from responses that many parents/carers were excluded from being involved in discussing support, particularly for those individuals with less complex needs that appeared to be able to advocate for themselves.

### ***Transitional Support***

**Q27 Are you receiving adequate support if you are going through transition from student/school services to adult services?**

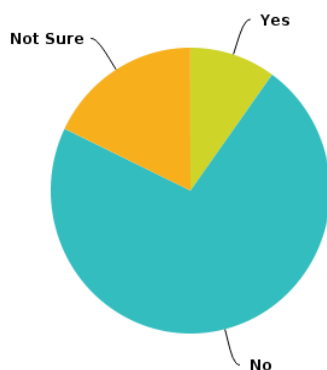
Answered: 395 Skipped: 707



Transition remains a key period in an individual's life and the vast majority of respondents who are currently experiencing transition support describe this as less than adequate. Further work needs to be carried out to improve this. Early intervention, and well supported transitions is widely recognised as the key driver in improving outcomes and also delivering less costly solutions as crisis situations are less frequent.

**Q28 Did you receive adequate support from your local transitions team to help you in the move from childrens to adults services if this took place since 2010?**

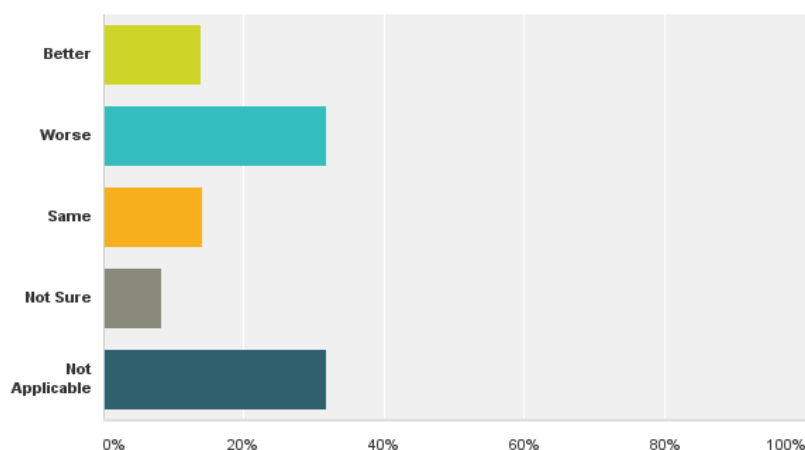
Answered: 403 Skipped: 699



The trend from Question 27 is replicated in the respondents who received transition support prior to the Autism Strategy being launched. This would suggest that the Autism Strategy has had little impact on improving Transition Support.

**Q29 If you are over 18 now, how would you compare your support from when you were under 18?**

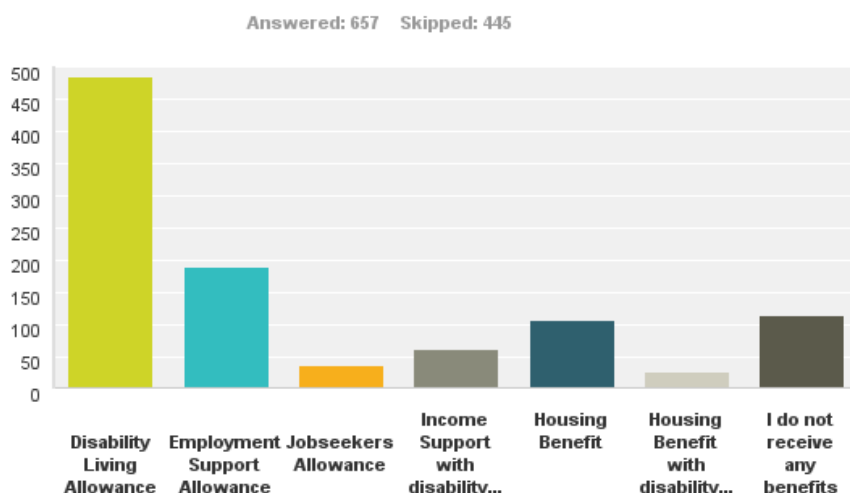
Answered: 603 Skipped: 499



46% of respondents report that services are either worse or the same as when they were under 18. This is also reflected in comments where a number of people report that high quality Adult services mostly provided by the Specialist Autism Charities across the country. 14% report that services are better now they are over 18.

### ***Getting the Right Support and Services***

#### **Q31 Are you in receipt of any of the benefits listed below?**



We asked respondents to highlight what benefits they received. The data below shows a high proportion of respondents claiming Disability Living Allowance and Employment Support Allowance. It also highlights that 113, which was 17% of all respondents did not receive any benefits at all. Few commented on the difficulties applying for benefits, with one noting that “**I stopped claiming DLA as the forms put me off.**”

Out of 655 respondents only 26% had been made aware of personalised budgets and how to access these to take control of their own service provisions.

In addition to this a staggering 60% noted that they had not been involved in meetings with statutory services where their own support was being planned, with one comment made noting a complete lack of awareness of meetings that took place about themselves. “**I didn't even realise that there were statutory meetings and I wasn't even told about them**”

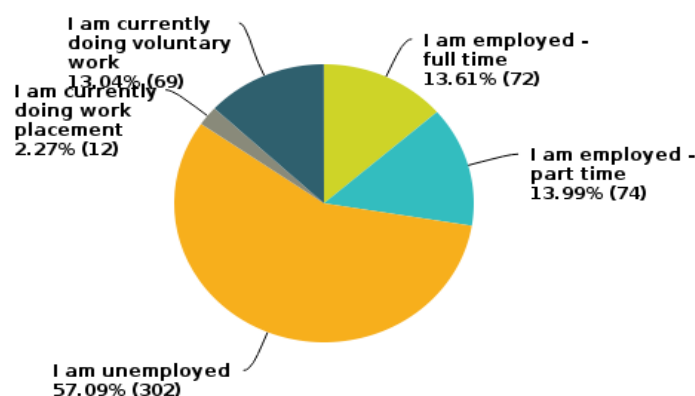
Another parent noted the difficulties accessing support or funding unless being categorised as having critical needs. “**People who do not meet the substantial needs criteria for adult social care are being left isolated without support and without support in a crisis. If my son did not have his parents (who retire soon ) he would have no one to turn to**”

## Work

Fewer individuals responded to this section of the survey with many choosing to skip this section as not being relevant to them at this current time. Out of a total of 529 who did respond a high proportion of those are unemployed, with only 26% being employed full or part time. If looked at in a context of all respondents to the question it could be assumed that the significant proportion of the 573 who skipped this survey are also unemployed. Based on the data below there 72% of those responding to this question are currently not engaged in paid employment.

### Q37 What is your current employment status?

Answered: 529 Skipped: 573



We asked respondents if they were aware of the support available to them from Access to Work, the governments support for individuals with health conditions in paid employment. Data shows that only 16% of respondents were aware of this service or how to access it, with only 4% actually receiving support from this service currently.

We asked respondents about their experiences of using Jobcentre Plus services, the table below shows the percentage of respondents that had accessed different services at the Jobcentre. None of respondents had received support from the Vulnerable Customer Team and only 1% received support from the visiting service. A higher proportion of individuals had accessed support from Disability Employment Advisors, this being 32% of respondents.

I have accessed front of house services i.e. signing on, etc	8%
I have seen a Disability Employment Advisor	32%
I have had support from the Vulnerable Customer Team	0%
I have had Benefits help	4%
I have seen a Personal Advisor	8%
I have had support from the Visiting Service	1%
Not Relevant	47%

Whilst individuals had received support only 13% of those who had received support suggested that it had met their needs at the time. 74% of respondents reported that staff that had supported them had not understood their needs at all or had only understood their needs some of the time. Only a low 2% of individuals said staff supporting them had understood their needs all of the time.

Only 14% of respondents noted that Jobcentre staff spoke to them about all the different options available to support them in finding work.

We were keen to capture data on the customer journey and the types of provision individuals with autism and related conditions were accessing.

9% - 54, respondents had been referred to the Work Programme, whilst

4% - 26 respondents had been referred to Work Choice.

Of those that had been referred to the Work Programme, 79% stated that the staff working on the programme either did not understand their needs at all or only understood their needs some of the time.

This is almost identical to the awareness of those staff working on the Work Choice, with 82% of respondents noting that the staff working on the programme either did not understand their needs at all or only understood their needs some of the time.

Some individuals commented on their specific circumstances and fears around accessing employment services and losing their current support. Some individuals also commented on the fears of accessing support whilst in work.

**“When living in residential accommodation the system would not easily allow having a job”**

**“Completing Employment Support Allowance forms to confirm that my daughter has very complex needs has been difficult as they do not reflect her needs.”**

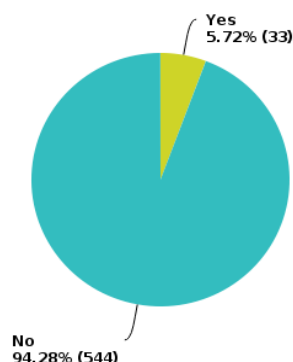
**“The disability adviser at the job centre was good but at the time employment was not appropriate as I needed significant therapy before I could start working, so I was moved to Employment Support Allowance. I am still waiting to get the therapy I need to move back into the workplace”**

## Developing Local Services

We captured data on local Autism Partnership Boards and how well they engaged with individuals with autism locally. The vast majority of respondents, 83%, do not know or are not sure if their Local Authority has an Autism Partnership board. Linked to the previous question, the awareness of Autism Partnership Boards is low and it would be anticipated therefore that the number of people attending these would be small. It should also be expected that people with Autism may find the perceived environment of a 'Board' meeting to be intimidating therefore not engage with them unless reasonable adjustments are made.

### Q51 Do you attend your local Autism Partnership Board?

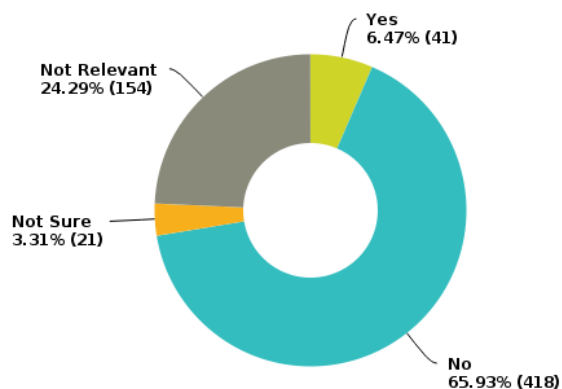
Answered: 577 Skipped: 525



We asked respondents if anyone had spoken to them about housing options available to them, with only 6% stating yes, they had been made aware of options, and 66% of respondents having received no information on the types of housing available to them. When analysed against 79% of respondents are either living with parents/ family or their partner, you would not expect a high proportion of respondents to have been spoken to by the local authority about housing options outside of discussing benefits.

### Q52 Has anyone from the local authority spoke to you about the different housing options available to you?

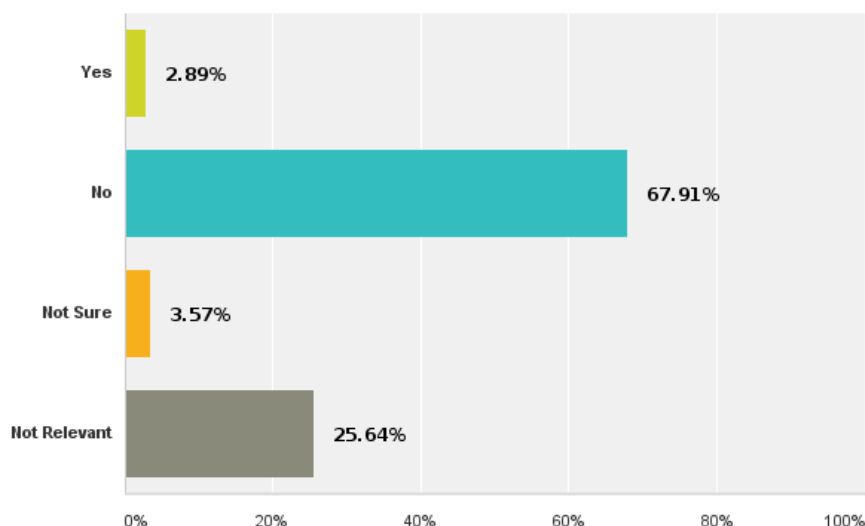
Answered: 634 Skipped: 468



We asked respondents if the advice they had been offered helped them understand how housing changes would affect their financial situation.

**Q53 Have you been offered any advice on how different housing options will affect your financial situation?**

Answered: 589 Skipped: 513



The survey captured many concerns of individuals in accessing support, barriers to accessing support, lack of understanding of local provisions, as well as not being able to access support due to eligibility criteria. Below are a few of the comments left by respondents.

“I am exhausted at trying to access support and having to constantly resort to legal means.”

“The local authority autism board does not appear to discuss these concerns.”

“How can one find out about support? My GP does not seem to know anything specific about ASD and she is the only professional I have contact with.”

“There is no support if your needs are not "critical"”

“We have not been told anything. Our main concern is a job. If housing were a concern, we would have to find out how to navigate the system. I'm not sure how we would start.”



## **Good Practice**

We asked respondents if there is an example of good practice that has made a difference to them.

Respondents left 268 comments. The key themes from these are described as follows:-

- **The need for flexibility:** being able to get the right support at the right time. Not shoe horning people into a process or system, but treating them as an individual and adapting support mechanisms to suit the person.
- **Importance of high level of awareness of those in first point contact:** Ensuring that gatekeepers to services have an awareness of Autism. Gatekeepers could be social workers, GP's, employers etc. Where these gatekeepers have a good understanding of Autism the experience is significantly improved for the individual.
- **Importance of looking at the family's needs as a whole:** Ensuring that the whole family's needs are taken into account through assessment processes. Enabling parents to advocate for their children and not 'shutting parents out' due to official process can also have a significant improvement on how individuals with Autism experience services / access opportunities.
- **Peer support is vital:** Peer support for parents and individuals from people who have share experiences.
- **Good Advocacy Support:** Having a good advocate who can put forward an individual's point of view.
- **Multi-agency approach:** Taking a multi agency approach so that duplication of meetings / assessments is reduced. This can also increase how quickly decisions and actions can be taken. Also ensuring a single point of access to services so families and individuals only need to get to know one person who knows their case well.
- **Listening to individuals:** Co-production with Service providers and Local Authorities.
- **Being able to access support locally:** Having local support, appropriate to individual needs.
- **Consistency in support:** Consistency of approach and having a lead person who the family and individual can get to know.
- **Structured, clear communication:** Ensuring communication is structured, delivered in a format that is understandable and checking to make sure that it has been understood.
- **Early Intervention support:** Funding preventative interventions that can avoid more costly interventions.

Some of the comments left are shown below;

**"The XXXX Trust who are based in Manchester have gone the extra mile to help me and explored lots of possibilities for leisure/ voluntary pursuits. They have organised meetings for me and really tried hard to support me"**

**"The new Prevention and Assessment Team for Working Age Adults have been really helpful and have been supporting me through the process of applying for a job with the county council."**

“I've found the XXXXXX Autonomy group (in general) to be very helpful - although I found out about them via LinkedIn rather than via the local council.”

“The understanding shown by an employee at the Citizens Advice Bureau and also by a Case Worker from our Carer's Centre both made a big difference to me.”

### ***Barriers to Support***

We asked respondents if there was an example of a challenge or barrier that was stopping you getting the most out of the Autism Strategy.

The key themes are outlined below from the 306 respondents.

- **Limited availability of local specialist services:** Individuals still having to travel out of area for support or not being able to access support to suit their needs when they need it.
- **Being seen as “too able” to require support :** People with High Functioning Autism / Asperger's Syndrome report that they are still falling through a gap in the system as they do not meet eligibility criteria for extra support.
- **Falling between social care and mental health:** Individuals feeling they are still being pushed between services and not fitting into a typical category of support.
- **Communication barriers:** Difficulties communicating own needs or receiving support in the first stages to do this.
- **Lack of GP Support/ Awareness:** GPs not referring individuals on for diagnosis
- **Funding:** barriers to accessing a diagnosis due to funding restrictions.
- **Not knowing where to start:** Being overwhelmed by too much information – one support pack with all information combined.
- **Local services not making adjustments to enable individuals with autism to access them effectively:** Austerity measures continue to have a negative impact on accessibility of support services across the board.
- **Individuals being unable to advocate for self:** Parents are often excluded from conversations and decisions. Individuals needs better access to good local advocacy services.
- **Not knowing where to go for information:** Needing a central contact point.
- **Awareness of the strategy itself needs to be communicated more widely.**

Some of the comments made on this section include:

“More Autistic specific services - eg a gym designed for people with Autism and their needs first of all and then include other people from other communities if they want to.”

“I'm seen as too high-functioning to 'need' support by services despite being encouraged to access support by the local autism strategy board. Services must provide support for high-functioning adults with Asperger Syndrome as we DO NEED support.”

“Transition and person centred planning is not taking place so it can't be used to inform future service planning. Effective planning from Year 9 and input from relevant agencies needs to be put in place.”

“I am very independent and in good health, and this has made me ineligible for social help from the local authority.”

“XXXXX is a very good borough for autism in children. There is a lot of help and support. There is nothing for adults and this is when you need help the most. XXXXX adult services say they are providing what is statutory and therefore fulfilling their duty!”

“There doesn't appear to be an effective Autism Strategy in XXXXXX - much talk and setting up of services has been talked about, but there is nothing that we can access in our part of XXXXX as far as I know.”

### ***Final Comments***

We asked respondents to make us aware of anything else they would like us to note when reviewing the findings of this report. Some of the comments noted include;

“Parents and siblings are an unused source of experience and information gained at first hand for training the uninitiated in Autism-specific awareness.”

“The XXXXX Autism Strategy Board are now combining the strategy with improving Child services and Transition services to make a seamless, smooth progression into adult services. But this is only going to affect those coming up through child and transition services so that they have adult services when they become adults. It is not tackling the issue of adequate services for those who are adults NOW.”

“There is still an enormous negative stigma attached to Autism. More needs to be done to stress the condition as just a difference from the "norm"; also to point out the special abilities of people with Asperger's like conscientiousness and attention to detail, etc.(which a tiny minority of employers have grasped and now target people with Asperger's as good employees).”

“More support needed for adults who live with families because its the families doing all the supporting but not getting support for themselves”

“You cannot access the help which is available if you cannot get an official diagnosis. More needs to be done on providing diagnostic facilities.”

“There is not enough awareness of how much preparation and 'recovery time' people with autism need in order to cope with an interaction with other people and the associated stresses.”

“I feel I have been let down by the NHS and the education system as, despite so many signposts during my life, nothing was ever done to help me and my family.”