



“My Mother will shoot me if I collect any more bus timetables or road maps”

## Overview

In April 2014 the government published "Think Autism, Fulfilling and rewarding lives, the strategy for adults with Autism in England; an update.

The update to the 2010 strategy sets out the new challenges people with autism and other stakeholders have set

15 priority challenges for action have been identified where further change is required.

With the new government strategy update it is time to update our local strategy, in order to do this effectively we need to involve people that are on the Autism spectrum and people that have knowledge of the spectrum including parents and carers.

All of the feedback and comments will be collated and will form part of the new strategy for Leicester, Leicestershire and Rutland.

The final strategy will be published online.

Consultation for the Autism Strategy has taken place utilising several different groups / formats, including;

- Feedback from carers at the Autism Carers meeting, a bi-monthly meeting held jointly with Leicester City Council and the Carers Centre.
- Workshops at The Monday Club, a weekly service user group for people with Autism
- An online questionnaire

The online questionnaire was promoted via Translate, a user led group, it was published in the Monday Club newsletter ( which is sent out to 164 individuals on the spectrum ) and it was sent out to members of the Autism Strategy group to promote across all networks.

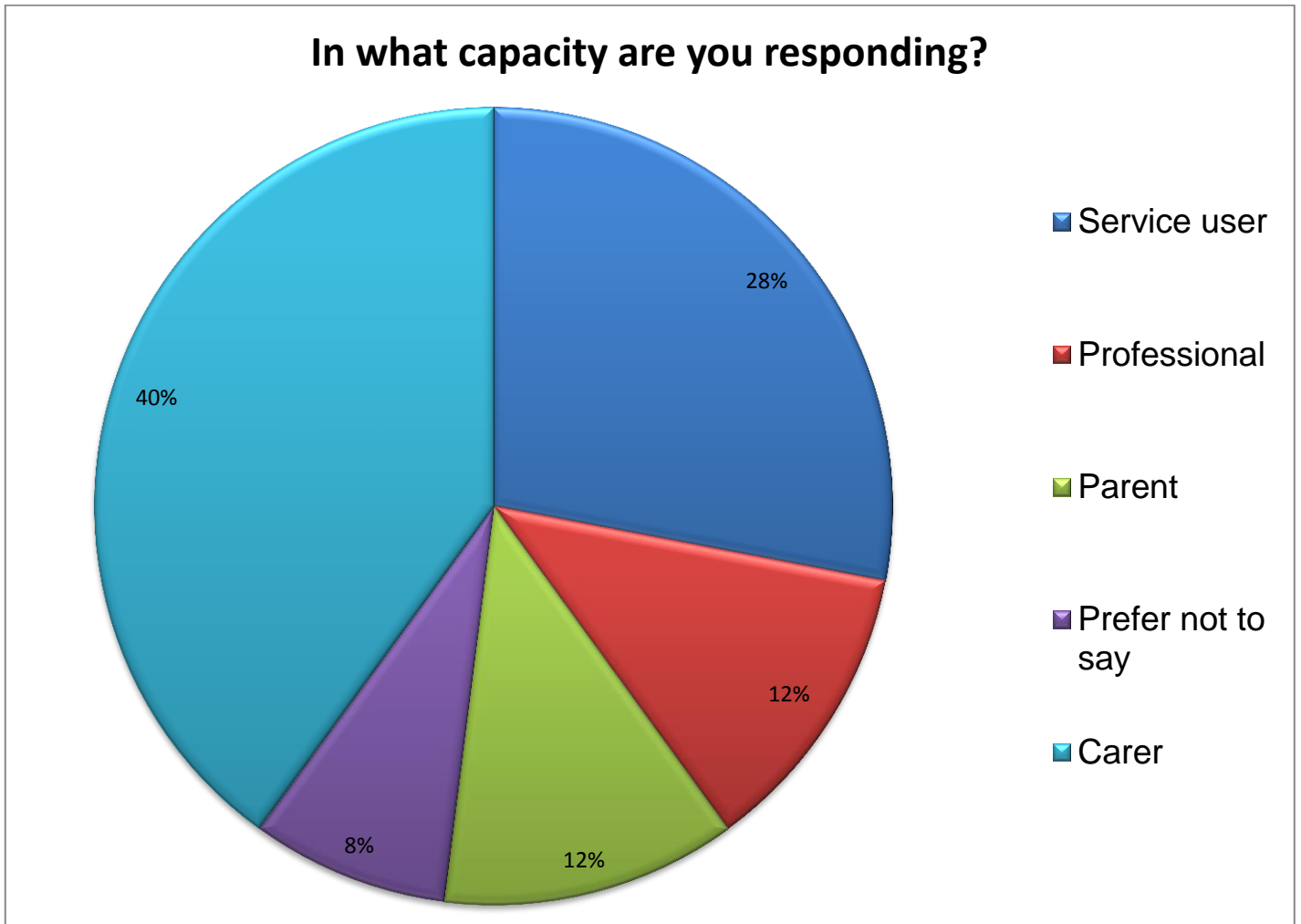
Of those filling in the online survey the majority were parents or professionals, with only 13% of the online responses coming from service users ( despite many professionals thinking that an online survey would be a preferable way to be involved for people that are on the spectrum )

20% of online responses came from professionals, all of whom are working with people on the spectrum.

It is interesting to note that both the option of parent and of carer were given on the online questionnaire, and no one chose to class themselves as a carer, ( with all of

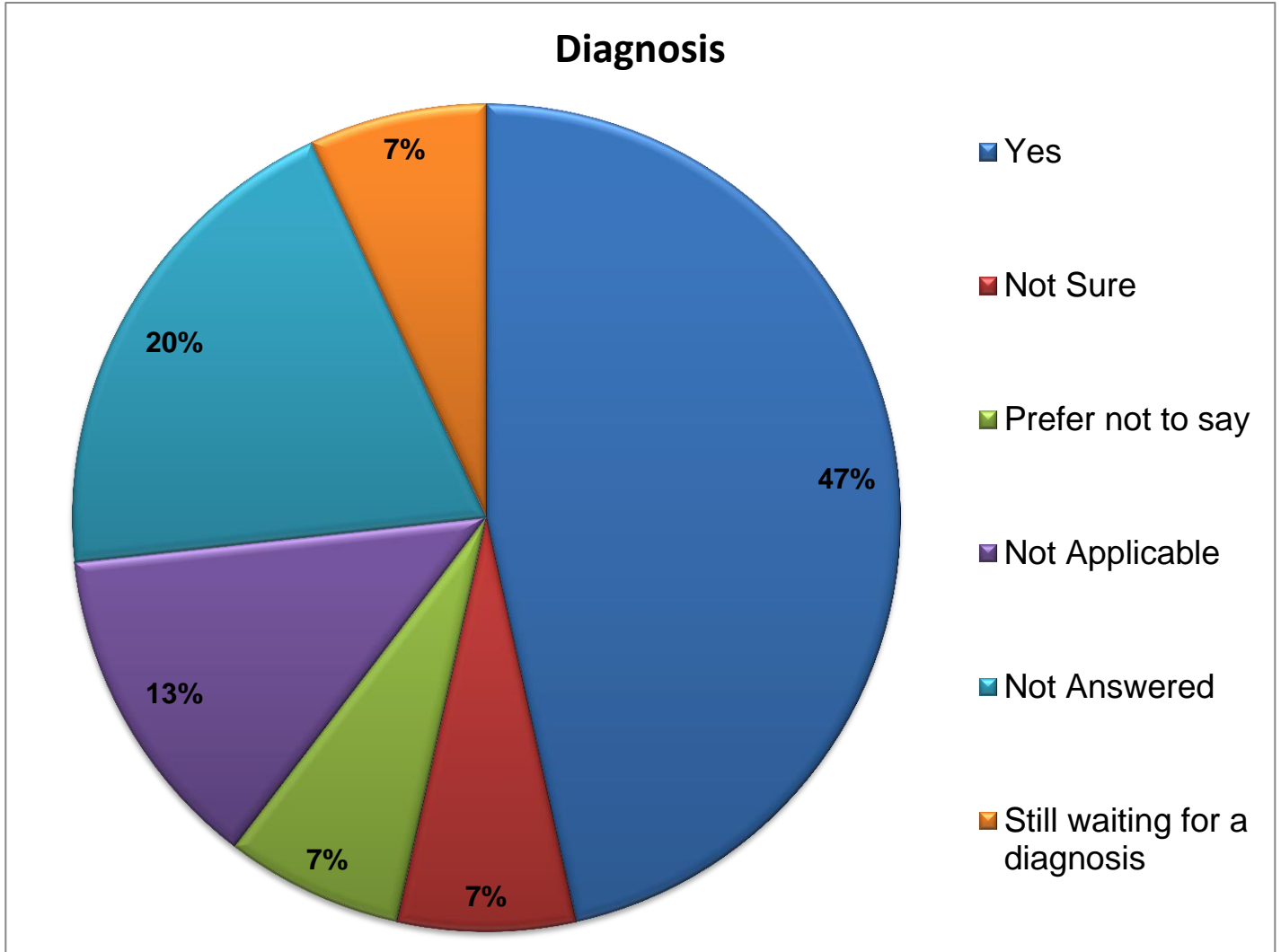
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the carers responses coming directly from the Carers meeting ) although 20% of online respondents did class themselves as a parent.



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**Question 3: If you are a service user have you had a clinical diagnosis?**



Option	Percent of All
<b>Yes</b>	<b>47%</b>
<b>Still waiting for diagnosis</b>	<b>7%</b>
<b>Not Sure</b>	<b>7%</b>
<b>Prefer not to say</b>	<b>7%</b>
<b>Not applicable</b>	<b>13%</b>
<b>Not Answered</b>	<b>20%</b>

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- I felt like I was treated like a guinea pig
- I am currently being assessed at the Aspergers Diagnosis Centre by Professor Brugha at Leicester General Hospital site. I am 48 years old and had to ask for a referral from my GP.
- 2 year wait for diagnosis of autism
- Approx. 70% of students with ASD attending Stephenson college not had a diagnosis

## **If you have had a diagnosis was it difficult to get?**

All of the service users that attended the workshop at the Monday Club had difficulties in getting a diagnosis, with comments including;

- It should take a maximum of 2 months
- There should be other places to go apart from your GP
- My parents paid 3k to a specialist
- My Step Mum had to fight for 20 years to get a diagnosis for me

Other comments from the online survey and the carers meetings included

- Son's diagnosis was hard to obtain. Finally given as Classic Autism by Dr Elizabeth Newson in Nottingham, only verbal given in Leicester at the time.
- We had to leave Rutland to get a dx. what happened in our sons case was shocking - yes he is a child still but will be an adult at some point and those experiences he has had as a child will stay with him until adulthood
- I was over forty years old when I got my diagnosis at the Bradgate unit in Leicester. After I lost my job my mum fought hard to get a diagnosis for my condition which I have suffered with all my life.
- Probably wouldn't have been got without parents working in professional fields

The parents attending the carers meeting felt that;

The current diagnostic pathways are not being followed and it is particularly difficult getting a diagnosis for those who do not challenge services, do not or will not engage, or are unwilling to accept a diagnosis and/or support.

Carers agreed that diagnosis should lead to support – otherwise just a label – but those without diagnosis need some support too.

Some individuals find it hard to accept that they have a diagnosis, especially when the diagnosis has come late – e.g. teen years or later

“If s/he's no trouble at school, you won't get a diagnosis”

## **The Governments 15 priority changes for action**

- 1. I want to be accepted as who I am within my local community. I want people and organisations in my community to have opportunities to raise their awareness and acceptance of autism.**
- 2. I want my views and aspirations to be taken into account when decisions are made in my local area. I want to know whether my local area is doing as well as others.**
- 3. I want to know how to connect with other people. I want to be able to find local autism peer groups, family groups and low level support.**
- 4. I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am. I want the staff who work in them to be aware and accepting of autism.**
- 5. I want to be safe in my community and free from the risk of discrimination, hate crime and abuse.**
- 6. I want to be seen as me and for my gender, sexual orientation and race to be taken into account.**
- 7. I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process.**
- 8. I want autism to be included in local strategic needs assessments so that person centered local health, care and support services, based on good information about local needs, is available for people with autism.**
- 9. I want staff in health and social care services to understand that I have autism and how this affects me.**
- 10. I want to know that my family can get help and support when they need it.**
- 11. I want services and commissioners to understand how my autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies.**
- 12. I want people to recognise my autism and adapt the support they give me if I have additional needs such as a mental health problem, a learning disability or if I sometimes communicate through behaviors which others may find challenging.**
- 13. If I break the law, I want the criminal justice system to think about autism and to know how to work well with other services.**
- 14. I want the same opportunities as everyone else to enhance my skills, to be empowered by services and to be as independent as possible.**
- 15. I want support to get a job and support from my employer to help me keep it.**

Everyone was asked if they agreed with the government's 15 priority changes for action, and **100% of those that responded** agreed with all of the statements.



**I want to be accepted as who I am within my local community. I want people and organisations in my community to have opportunities to raise their awareness and acceptance of autism.**

- Lack of understanding the complexities of autism means that people often belittle the impact it has on individuals and their family (particularly emotional and the need for extending social interactions and understanding that withdrawing is not always an informed choice etc.).
- If people have understanding of what Autism is then it means we all have a better chance of moving forward as one whole community.
- You can't make people understand or empathise, but the more opportunities that are available to meet, speak and discuss autism will allow some pathways for acceptance and understanding to begin.
- So that people with autism are able to access more clubs or activities
- Because people with Asperger's need help from organisations and support
- It should happen

**I want my views and aspirations to be taken into account when decisions are made in my local area. I want to know whether my local area is doing as well as others.**

- Past experience has informed me that voices other than statutory voices can make a difference if we work together.
- If I live in an area I want to feel confident that it is for me and my needs as well as for the needs of others.

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- Being in Rutland services are dire - there are so many children/adults that go under the radar for services
- It is vital for those with autism/asd, etc. to feel included in locality issues. However, for those with these conditions to be actively involved will take much time to get used to due to the newness of these concepts.

**I want to know how to connect with other people. I want to be able to find local autism peer groups, family groups and low level support.**

- Need more support groups in the city – especially for under 18's
- Linking in to each other is important it can give knowledge, ideas and emotional support depending on the group. It can also make you feel slightly less isolated, something that can often happen to families with people who have autism.
- Support for people with Autism is needed so when issues arise we have somewhere to share them with so we can find positive solutions.
- Online support and sign posting must be streamlined to provide a facility for the individual to choose their own support. The most valuable constant support I have accessed is through my sons' sibling service which has slowly brought me in touch with Hinckley parents, and also separate groups within Leicestershire county/city. We went camping for the first time this year which was wonderful. But it evolved extremely slowly compared to neurotypical groups due to the 'fear/uncertainty' of new situations, which is very stressful
- It is important to be able to chat to people who feel the same
- Have and its helpful

**I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am. I want the staff who work in them to be aware and accepting of autism.**

- Using language in letters that is not suitable for the target audience
- If they do not understand autism how can they make reasonable adjustments? It would also be helpful if families and the person who has autism had access to what is considered a reasonable adjustment and why.
- I agree with this because it means people will be aware of my needs. This means I can live within a community not there looking in.
- I am a newly qualified social worker in adult services, and have a son with Asperger's as well as being assessed myself and I still don't know everything about what 'reasonable adjustments' are. I do know that some do not understand that I can hear noise that are not loud and feel nauseous if anyone eats at their desk. I stress out about entering the open plan office, and finding a free desk in a  
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hot desk environment. I need 10 mins to sit and recover from the journey into work and walking through the office. It would be easier for me if my colleagues understood this, and just because I don't say hello or make eye contact that I am not strange, just struggling!

### **I want to be safe in my community and free from the risk of discrimination, hate crime and abuse.**

- My son needs to be kept safe from others and vice versa. People do not understand his difficulties at times and as a result we have in the past been asked to leave a café, been spat at, had eggs thrown at us because we were easy targets. I did not particularly like as a parent hearing from people in the street that they know what they would do if it was their child. It makes it hard for families to include their children when this happens in normal social activities. This makes it even harder for the individual to learn social rules.
- Knowledge helps people accept.
- As a 10 year old child one of my sons has been subject to abuse
- More education and understanding about asd, etc would reduce the risk if verbal and physical abuse. But education starts at school, and many teachers have absolutely no idea about autism, etc. They tend to work from the concept of neurotic parent, and unless there is medical advice to suggest otherwise and of course there may be no academic problems if the child is 'high functioning'. The condition needs to be discussed in depth at school during citizenship, SEAL lessons, and provide some interaction and knowledge for the home environment to become involved in. Mindsets need to be changed, and this takes long periods of time.

### **I want to be seen as me and for my gender, sexual orientation and race to be taken into account.**

- Loss of identity – “Mrs. H replaced by M’s mum”.
- I would like my son to also be given support to understand his sexual rights and responsibilities and have support to relationships if he chooses and when (if he does) he indicates that he would like a relationship. This is not an issue at present as he does not like sharing his accommodation with others, but if it came up I would like the support to be there.
- Knowledge helps people understand.
- Everybody is an individual and strengths need to be encouraged and appreciated. At school, everybody has to aim for the same qualifications, in fact top grades, too. This is unnecessary pressure for those that are able to contribute to the economy

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and society in a more specific direction. League tables should be used only as general information, not as the only way to gaining individual 'success'.

**I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process.**

- We got the written diagnosis before he was 5. Fortunately we knew before he was 2 what the issue was thanks to an article in a monthly magazine. It still took some time and a lot of effort to get the verbal diagnosis and then a written one. Without it and the support he had including me volunteering in autism specific schools to support him he would not be the relative success he is (which we and professionals alike) are proud to have been part of. The prognosis for children like him was generally very poor, working and understanding the impact of autism not thinking of him as having learning difficulties made the difference. It meant we looked at the autism problems that caused his comprehension difficulties not seeing it as his inability to learn, just as more convoluted and needing to be presented in his way not ours. This has to keep being taught to his workers to see the world from his perspective not theirs. It makes a big difference. It does not mean he gets all his own way it is just that explanations have to take into account how he sees things.
- When there is understanding things should move forward for everyone. Stops anger and frustration.
- 5 years to dx my younger son and within 2 years of that dx he was in an independent asd school and yet certain professionals in the area still do not believe he has autism
- Children and adults have not been diagnosed soon enough which has had a massive impact on their mental health, possible detrimental effect on physical health, relationships, employment and educational attainment. Speed is of the essence, I cannot underline the importance of this fact enough. Late diagnosis has a detrimental effect on many lives not just that of the individual concerned.

**I want autism to be included in local strategic needs assessments so that person centered local health, care and support services, based on good information about local needs, are available for people with autism.**

- ASD affects at least 1/100 people when I was first involved 4/10, 000 was the quoted figure. The reality is it affects a lot of people and the people who care for them. Understanding autism and knowing how better to work with it from as early an age as possible can improve the lives of many and hopefully prove to eventually be more cost effective. It is a long term investment though as with the

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right support more might at least be able to do voluntary work.

- Autism is part of many people's lives and should be included we are part of a community.
- I want professionals especially in the LA to understand what asd is and that it is a spectrum and not just make assumptions that it's the same for every person
- I agree, but every case is different, and there is much stigma associated with social services and mental health which creates a barrier in addressing needs, and accessing services.

### **I want staff in health and social care services to understand that I have autism and how this affects me.**

- Changing appointment times with no thought as to the impact of the change
- Carers agreed there was a need for a proactive approach, for example to prepare an individual now, ready for an "unannounced" fire drill that would break the usual routine.
- If they understand it makes a massive difference. For my son it has meant fantastic support because staff have listened to me. I should not see this as the exception it should be the norm. I am talking about mainstream services as well as specialist ones. It has also meant he does not always only access specialist support. He uses the specialist when needed but where possible we then generalise it down to ordinary community support levels.
- Knowledge is essential for my care needs.
- My life is not defined by autism, and it can be easy to become drawn into a life dictated by autism, rather than looking at the individual as a human being in society, and inclusion not isolation.

### **I want to know that my family can get help and support when they need it.**

- Very little support and communications – have to do it yourself
- Carer excluded from meetings with other professionals
- Carer not on the internet – so difficulty in accessing information
- Carers left to do it themselves
- Schools don't always communicate effectively
- Poor communication
- Lack of knowledge, carer attending meeting to learn what is available
- Siblings are largely unrecognised and under-supported. There are some sibling groups that meet around the county.
- Some families can't accept the stigma of caring for someone on the spectrum, or

do not believe that the diagnosis is accurate – often because the criteria seem vague and open to interpretation.

- It was a lot of hard work finding out information and rights. It has taught me a lot and my son takes what he has for granted as he does not know how difficult it can be for families. It was an experience what I have gone through over the last 29 years, but it is not something I would wish others to have to go through, other than by choice. Constant negotiating for rights for your son and others like him is really hard graft along with also providing his care.
- Living with Autism can lead to families requiring help and support. I want my family to know it is there when needed.
- Mum would like a break from fighting for services please
- One point of contact, widely available, and with access to services and referrals, highly experienced and knowledgeable in the field, with local knowledge too. Somewhere you can trust in getting the right advice, impartial, and most important is stability and consistency - name changes, people turnover and goal posts moving all provide barriers when accessing services. I like to speak to the same person, who understands, and will be there next month when I return to ask the same question again.

**I want services and commissioners to understand how my autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies.**

- Transition has been a nightmare
- Controlled environment in school, not so when son leaves
- Difficulty in changing the routines as son gets older, so hard to get son to try new things
- It is crucial. It is also important to understand that although the autism can affect differently at different ages, often the same core difficulties are there if things go wrong and the individual becomes stressed and resorting to previous behaviours as a coping device. Autism is not static, how a person is supported, the environment, their personal health and all sorts of issues can make things easier or more difficult for the individual. This does not mean they cannot progress, it just means that sometimes a more complex progress route is used than what is expected.
- Change can cause disruptions more so to people with Autism. There needs to be things in place to help support people with autism.
- Knowledge of autism in individuals and continuity are extremely important factors in transition periods. Knowing people having been through similar experiences is

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also important, and the network of (peer) support can start early on in a child/parents life/diagnosis.

**I want people to recognise my autism and adapt the support they give me if I have additional needs such as a mental health problem, a learning disability or if I sometimes communicate through behaviors which others may find challenging.**

- Assessments need to take this into account. A lot of people who have autism are quite able given the right support, it is just understanding what support is needed to achieve this seems difficult for many professionals. My son is more fortunate than many but it makes it a constant issue for me negotiating why he needs the level of support he receives. It is negotiating I could happily wish I did not have to constantly do as his autism will not suddenly disappear.
- Autism is not the person's fault it is what it is and people living with autism have challenges that require support at different levels and at different times. They cannot always adapt, we need to learn and support.
- People who don't understand must have access to help and advice in order to support them in their role. Supervision is paramount, as if there is a lack of understanding or empathy then this will have a detrimental effect in all concerned. The police must also be involved as well as health and social care.

**If I break the law, I want the criminal justice system to think about autism and to know how to work well with other services.**

- General consensus that there were issues over the police in terms of Appropriate Adults. People on the spectrum could lose out or have an unearned criminal record due to failings in the system or missed opportunities.
- My son may have some understanding of right or wrong, but that does not mean he always has this. He knows not to cross the road if traffic is coming because he would get hurt. This does not mean he remembers to look both ways, to judge traffic and recognise when he can cross. He relies on pedestrian crossings but if he had a green man and an ambulance needed to go over on their red, he would not understand the need to stay on the pavement. The law can be the same.
- Autism cannot always adapt and be what the law says. Trained professional assessments must be taken into account so equality and fairness is seen to be delivered in the law.
- If the law does not understand, then the issues will not be addressed effectively, it is often lack of understanding by the service user rather than a criminal matter that needs addressing.
- Currently there is increasing anecdotal evidence of those with autism being more  
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susceptible to radicalisation via the internet. More community support and recognition from Health and the police on how to support individuals will be essential.

**I want the same opportunities as everyone else to enhance my skills, to be empowered by services and to be as independent as possible.**

- Independence is important. What is equally important is that the right level of support is provided to enable independence. With autism people often can do things themselves but need others to deal with other issues such as keeping them and others safe, helping concentration and keeping focused, planning and preparation etc. This needs to be understood if independence at any level is to be achieved. People also need support to understand that they can make mistakes, negative issues can be a big thing for many people who have autism (and their families)
- Everyone has the same right to the same chances in life where ever possible.
- Publicity and education at School and work will help those with autism to understand and build on their strengths.
- Many of those with autism are described as high functioning. Often it is not their academic skills which prevent them from finding work, but a lack of social skills/awareness and organisational support. with this in place most of those who struggle to find and maintain jobs are more likely to be able to do so. To achieve this, we need support from Social Care around daily living skills, mentoring support for social and work related skills via job agencies/connexions, plus ongoing support to develop these skills so that those with autism can reach their full potential.

**I want support to get a job and support from my employer to help me keep it.**

- It would be lovely, but support has to be there to be able to afford the level of care and housing costs etc. Benefits need to change to make it so that there is a tailing off but protection to help people to work. Also rules about volunteering need to be changed.
- Where possible anything can happen. We need to embrace rather than shun.
- I know many opportunities for employment have been reduced, as well as agencies with experience and understanding of autism have been lost. I anticipate that the only way forward in the current economic climate is the growth in social enterprises to manage this problem. This may have the unintended consequence of isolation from the rest of the community (exclusion), restrictions on creative attainment in employment, and low wages.

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## Getting involved

### Do you think we know enough about the needs of people with Autism?

80% of people that responded felt that not enough was known about Autism or the needs of people on the spectrum.

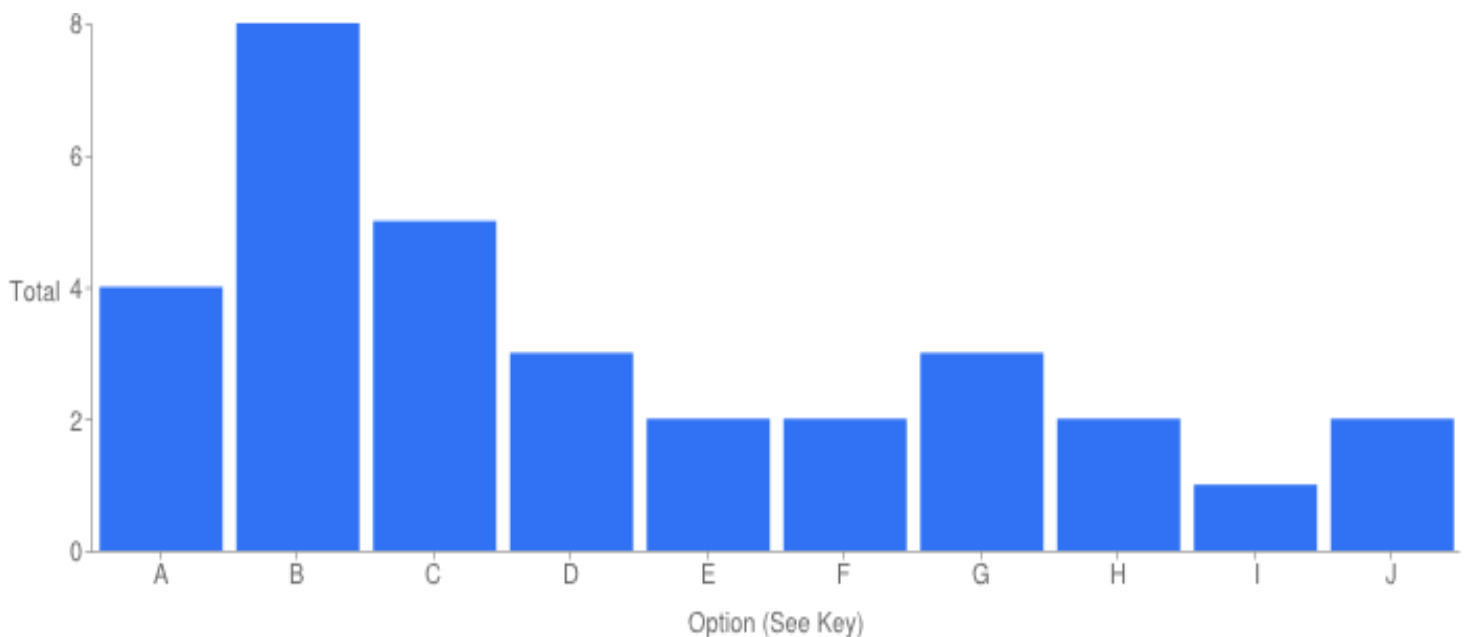
- My son is one of the lucky ones, most families and individuals do not have this level of support.
- Knowledge and support to families and the person who has ASD needs to start early. It should start before the child is 2. The earlier appropriate help goes in the better the chances are of reducing some of the more difficult issues becoming entrenched.
- Autism needs more positive awareness done so as a country we can learn together.
- Everyone has assumptions, they do a one day course on autism and think they know everything -some children with autism can make eye contact!
- Tap into national autistic society info, advice, and training; ask and be honest about what is available, give options and definite choices. This is a good survey.
- Up to date research, work with universities and local groups. Interact physically, not just via written words.



**If you would like to help the council get better at understanding Autism which of the following ways to get involved would you like?**

**( people could select more than one option )**

Key	Option	Percent of All
A	1 to 1 meeting with someone from the council	40.0%
B	Group meeting organised by the council	80.0%
C	Group meeting organised by peer support group	50.0%
D	Filling out a paper questionnaire	30.0%
E	Filling out an online questionnaire	20.0%
F	Discuss on twitter	20.0%
G	Discuss on Facebook	30.0%
H	Email with someone from the council	20.0%
I	Other	10.0%
J	Not Answered	20.0%



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I am already involved so however will suit me, except face book and twitter, I am not keen on them.

National government TV campaign

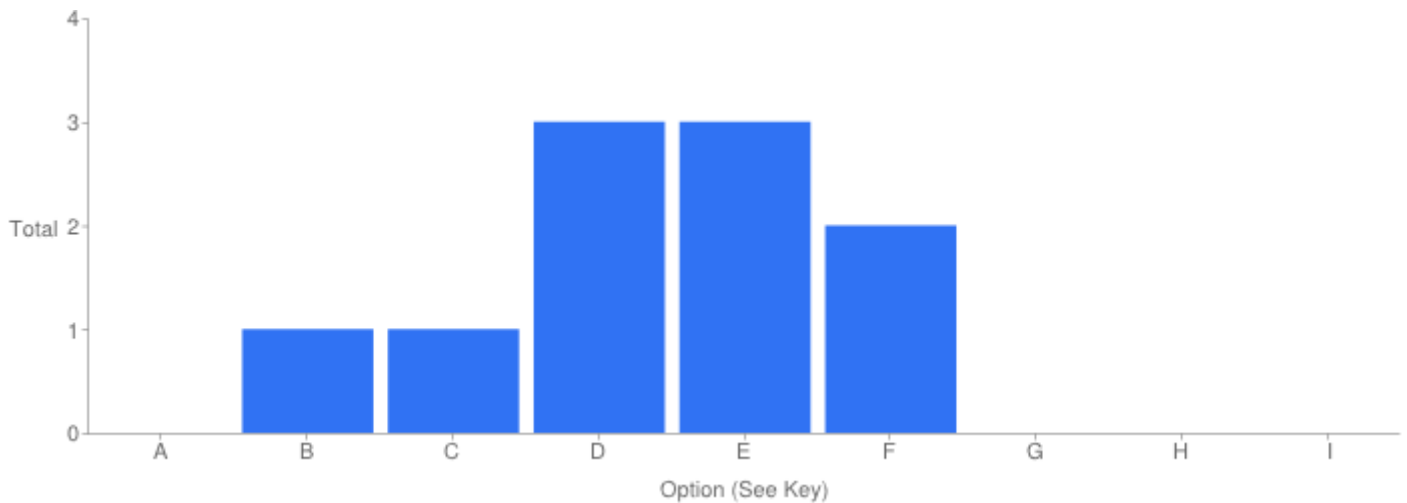
Depends what the issue is, all of the above - but too much information or choice may lead to complete shutdown and be ineffective when trying to engage. Softly softly approach, from small acorns, etc.

## About you

To help us analyse the data it would be useful to find out which area you live in

Key	Option	Percent of All
A	Leicester City	40.0%
B	Leicestershire County	40.0%
C	Rutland	10.0%
D	Other	10.0%
E	Not Answered	0%

Question 2: What is your age?



Key	Option	Percent of All
A	Under 16	0%
B	16 - 24	10.0%
C	25 - 34	10.0%
D	35 - 44	30.0%
E	45 - 54	30.0%
F	55 - 64	20.0%
G	65 - 84	0%
H	85+	0%

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### Question 3: What is your gender?

Key	Option	Percent of All
A	Male	30.0%
B	Female	70.0%
C	Prefer not to say	0%
D	Not Answered	0%

### Conclusion

Of all of those that had received a clinical diagnosis there was the general consensus that it was not an easy diagnosis to get.

People felt that there was not enough support for parents / carers throughout the process, with many people not knowing where to go to get help.

Service users believed that in some instances people only got a diagnosis because of the people that their parents knew.

Many people perceived getting a diagnosis as a long battle – stories of children being misdiagnosed, with anxiety disorders, leading to severe difficulties later.

Some people felt that even though they now have a diagnosis there is still an element of not being believed.

**Some work definitely needs to be done in order to improve the diagnosis process, a greater awareness for parents with more support.**

There is a need for a greater understanding and awareness of how being on the spectrum affects individuals – and this is needed across the board. Some people on the spectrum are struggling at work due to the lack of understanding as to how their autism impacts on them. It was felt that there needs to be some work for front line staff in how to support people on the spectrum – such as bus drivers, job centre staff, taxi drivers and housing repair workers etc.

**Free training is available, however a basic online awareness training course could potentially be made compulsory thus giving everyone the most basic awareness –**

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**but an awareness that could lead to much better customer service and support.**

That level of autism awareness training should also be something that any employer of someone on the spectrum undertakes.

When it came to jobs, there was a mixed bag of responses. Many of those on the spectrum chose not to tell job centre staff as they felt there was a lack of understanding and support available, so it was easier just to say nothing.

Of some of those in work there was a distinct lack of support in order to facilitate career progression – it was felt that they should be grateful for having a job, even if they didn't particularly like that job role and wanted to move.

**This is an area where a simple local campaign to raise awareness would work well.**

80% of all people thought that we don't know enough about the needs of people with Autism, this is something moving forward that we really should look to alter, maybe including it as a key performance indicator in future strategies.

One of the biggest surprises was when asked how people would like to get involved going forward 80% of the individuals responding said they would like a group meeting organised by the Local Authority ( with 50% saying a group meeting organized by a Peer group )

**Given that there is a need in some individuals of having a plan, a structure etc – then having a regular council led service user meeting, where individuals can help to put together the plan seems like an option worth exploring.**