

## Information and Advice Survey

A survey of 28 questions was circulated from 20.06.17 – 03.07.17 via Survey Monkey web link relating to the availability of information and advice, and evaluations of the Local Autism Directory facilitated by Autism Hampshire. This survey was aimed at children and adults with autism and their families and/or carers, or professionals that work with them. This forms part of the Hampshire Wellbeing Advice Service Project, in partnership with the following organisations and funded by Hampshire County Council:

- Age Concern Hampshire
- Autism Hampshire
- Citizens Advice East Hampshire
- Citizens Advice Havant
- Citizens Advice Winchester District
- Community First

A total of 134 responses were received, of which 23 were invalid leaving 111 valid responses.

### Summary

The majority of respondents were from the Hampshire local authority area (90.1%), followed by Southampton (7.2%). The majority of respondents who were from the Hampshire local authority area were from the Eastleigh Borough (18%), followed by Winchester City (15%). The majority of respondents were parents or carers of a person with autism (84.7%), followed by those who work with a person with autism (19.8%). The majority of respondents care for a person, or are, in the 7-11 age bracket (27%), followed by the 18-25 age bracket (23.4%). Just under half of the respondents care for a person, or describe themselves as, having Asperger syndrome or High Functioning Autism (49.6%), followed by autism with accompanying learning difficulties (35.1%). Most (93.7%) have a formal diagnosis of autism/Asperger syndrome.

The most popular category type of information that 67.6% of respondents were interested in was *learning and education*, followed by *social and leisure activities*, picked by 52.8% of respondents. Also very popular were *social care and support (including support for carers)* and *autism specialist service*, each picked by 41.7% of respondents. This result is possibly to be expected due to the high number of participants responding on behalf of children in the 7-11 age bracket. The least popular category was consumer issues. The other categories were ranked as follows:

- Health and wellbeing (38.9%)
- Finance including benefits and debt (37.0%)
- Employment (31.5%)
- Specialist support/services (30.6%)
- Relationships (29.6%)
- Legal issues (23.2%)
- Housing (19.4%)
- Transport (16.7%)
- Consumer issues (3.7%)

The most popular way by far that respondents seek information and advice was to go online. This is followed by attending autism groups, and then contacting voluntary organisations. The results reflect that going online is possibly the easiest and fastest way to find information, however speaking to other people in the same situation can have the same benefit. Going to the library was the least popular choice. The popularity of places to find information and advice are ranked as follows:

- Online (87.2%)
- Autism groups (54.1%)
- Voluntary organisations (35.8%)
- Family, friends and neighbours (33.0%)
- NHS (21.1%)
- Other professionals (solicitors etc.) (15.6%)
- Social care services (14.7%)
- Library (4.6%)

Our respondents were asked what sort of things make it easy to get the advice and information they need. The most common answer was use of technology to go online and look up useful information through internet search engines, or access online support groups via social media. Many respondents need to be able to access information out of working hours, or are not able to get out of the house very often, so being able to find information online from home at any time is very helpful. A “one-stop-shop”, easy to use website where the information was all in one place would make this even easier. Some also suggested that an accessible (local) out of hours drop in service would also help, to speak to a person to clarify what one may have read on the internet – although 16% of respondents said they would actually find it difficult to use a face-to-face service, and 13% would find a telephone service difficult to use. Other things that make it easy include:

- Speaking to other people in the same situation
- Support from school
- Knowing where to go/where to look
- Talking to professionals
- Feeling confident/safe
- Knowing a trusted advisor
- Increase in acceptance and awareness of autism
- Brief/bullet pointed/visual information
- Having time to research

A significant number of people (21) responded negatively to the question, stating that there is nowhere to go for help, or there have been problems with the help received. There were several comments that finding more information aimed at adults would really help. One person commented that their own determination makes it easy to find information, having a “conviction that if I don't find the answers and advocate for my children no one else will”.

The barriers to finding information were non-availability of autism specialist advice (58%) and information and advice providers not being autism aware (41%). Although going online is popular, the information is not easy to find (37%). A high number of respondents don't know where to look (36%), online or elsewhere.

## Specific Example

Our respondents were asked to think of a specific example when they received information or advice. There were 37 different organisations outlined in the examples, demonstrating the variety of information and advice available in Hampshire. Out of the 111 respondents, 69 gave an example.

Encouragingly, most of the responses were of positive experiences, with 48.5% of respondents rating the service they received as very good, and 33.8% good. The 36 different organisations named in the specific example included information and advice providers as well as organisations that provide specialist support, health sector organisations, support groups or schools (see table 1).

Out of those that received a good or very good service, the difference getting help made was great. 12 respondents felt more confident, less overwhelmed and better able to deal with the problem they needed advice with. Two people better knew their legal rights. However, of those that received a poor service, 13 reported that it made no difference to them. One person stated that “I was unable to obtain the advice I needed due to the inaccessibility”.

Please see appendix 2 for the full breakdown of the specific examples.

Table 1 – Organisations named in specific example section, with ratings.

	Very Good	Good	Poor	Very Poor
Adult Mental Health Team			1	
Autism Ambassador (in Hampshire Constabulary)		1		
Autism Hampshire	5	2		1
Autism UK	1			
autism unit outreach	1			
Basingstoke Autism Support Hub	1			
CAMHS				3
CAMHS Parent and Carers Events (PACE)		1		
Citizens Advice Bureau	1	1		1
Duty social workers		1		
Gateway Card staff		1		
Hampshire County Council Young Adult		1		
Health visitor	1			
IPSEA	2			

	Very Good	Good	Poor	Very Poor
Job Centre				1
Learning Disability Integrated Health team		1		
Local Education Authority				1
Local Offer Website	1			
Maudsley Hospital CIPP	1			
mental health social worker		1		
Mustard Seed Autism Trust	2			
NAS benefits line		1		
NAS South Hampshire Branch		2		
National Autistic Society	3	2		
No Limits		1		
Parent Voice	2	2		
SAIL	1			
School/College staff	4	3		
SENDIASS	1			
SenseCere	1			
social group		1		
Steps 2 Wellbeing				1
Support4Send	2	1	1	
The Zone	1			
Winchester Autism Group		1		
Yellow Door		1		

## Recommendations

- Make information and advice accessible online for easy access
- Make online information and advice easy to find
- Provide other means of accessing information and advice available for service users that cannot go online, such as walk in advice centres or a telephone service
- Advertise the existence of information and advice services widely, using a variety of media e.g. online, leaflets, by post, local news outlets and through community organisations such as GP practices, schools, charities and support group networks
- Provide more information and advice for adults
- Provide more autism specific advice and information

## Local Autism Directory (LAD)

The respondents were asked to spend 10 minutes using the LAD, and then to evaluate it. 79 respondents filled in this part of the survey. The respondents were asked to evaluate the autism information provision, homepage look and feel, ease of use and search engine efficiency. The provision of autism information received the highest rating, with 48.7% of respondents rating it as good.

When asked what they liked about the LAD a variety of responses were received, but the most popular feature was the volume of information it contains. When asked what they thought needed to be improved, the most frequently mentioned features were 'More provision' and the 'Homepage look and feel'. Most felt the homepage was too cluttered and text heavy, suggesting that it could be improved by using more graphics and buttons.

The responses have been analysed as follows:

What did you like about the LAD?	# mentions
Volume of information	22
Easy to use	14
One-stop-shop	11
Nothing	8
Layout	3
Search facility	3
Postcode search	3

What needs to be improved?	# mentions
Homepage look and feel	12
More provision	12
Nothing	11
Content	8
More comprehensive	6
Navigation	5
Keeping information up to date	2
Eliminate pop-ups	1
Text colour	1

When asked if they had used the LAD before, 53% of the 79 said that they hadn't, mostly because they hadn't heard of it before. When asked if they would use it again, 89.5% of the 79 said that they would. Encouragingly, 69.2% of the 79 found the directory useful, which is encouraging, however some felt that improvement to the content and appearance is needed before they would use it again. Some even found information that they were not aware of before as a result of answering this survey. The fact that the directory is a one-stop-shop is appreciated by many.

#### Recommendations for improving the LAD:

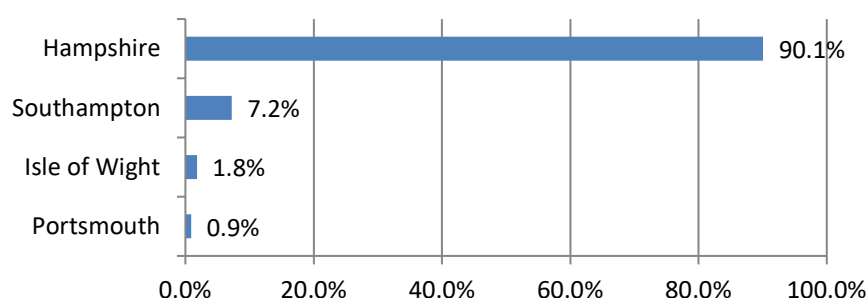
- Improve the homepage look and feel by removing text and replacing with graphics and buttons
- Make it easier to use by improving navigation and search engine
- Improve appearance on mobile devices
- Advertise more widely
- Keep information up to date
- Add in cross border information

#### Data Breakdown

A more detailed breakdown of the data collected follows for each question, with appendices for all questions for which open-ended responses were received.

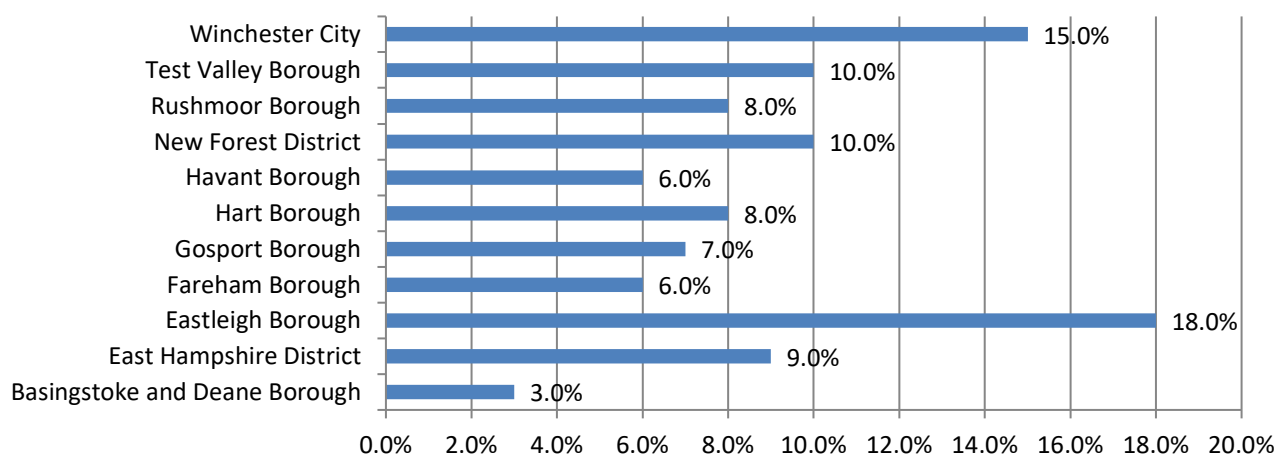
### 1. Which local authority area do you live in?

Answered: 111 Skipped: 0



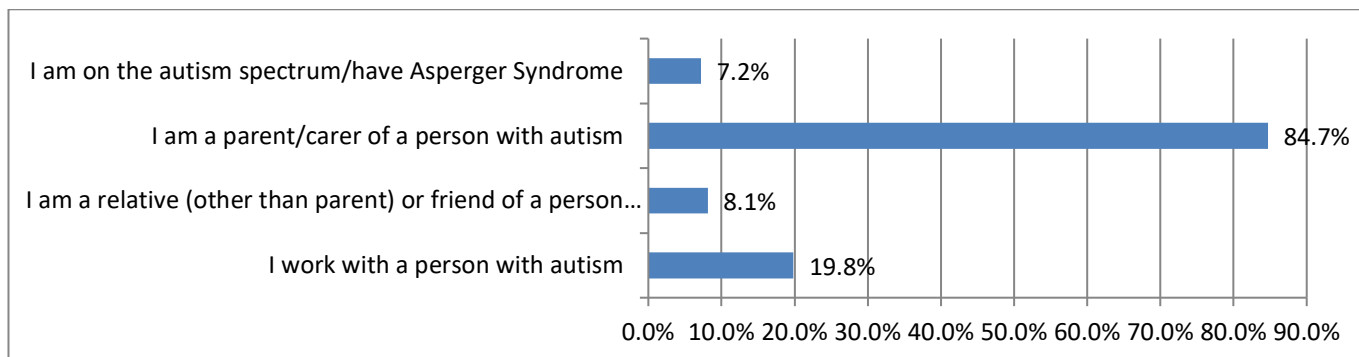
### 2. If you have answered Hampshire to question 1, which Districts/Boroughs do you live in? If not Hampshire please go to the next question

Answered: 100 Skipped: 11



### 3. What is your relationship with autism? (Please tick all that apply)

Answered: 111 Skipped: 0 (compulsory question)

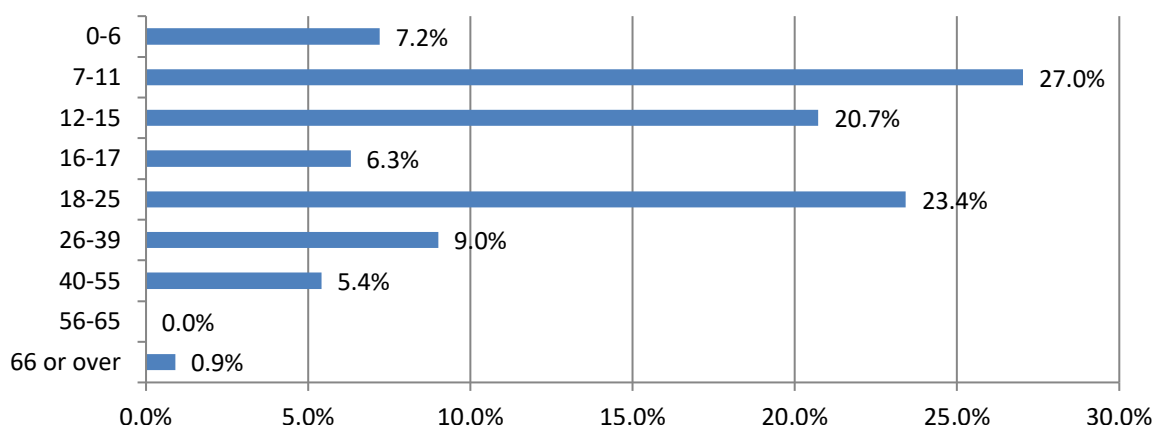


Other responses:

- I am in a social work team with a large percentage of children with ASD on my caseload
- I am also an Autism Ambassador and I coach trampolining for children with ASC
- I also run a support group for families who have children with ASD/mental health issues

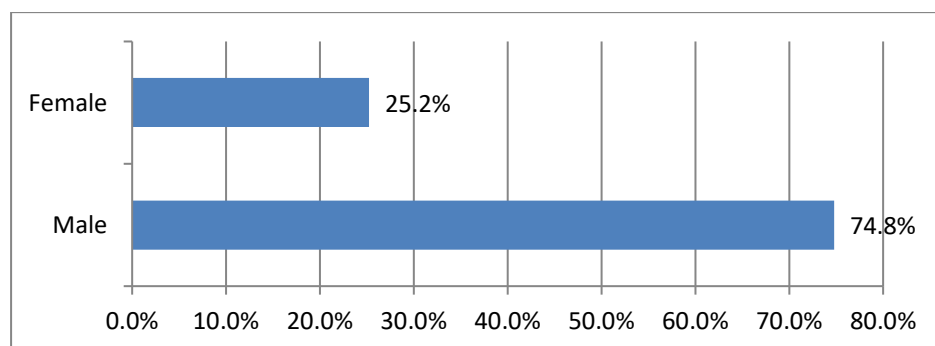
#### 4. Which age bracket does your person with autism/Asperger syndrome (or if this is you) fall in to?

Answered: 111 Skipped: 0 (compulsory question)



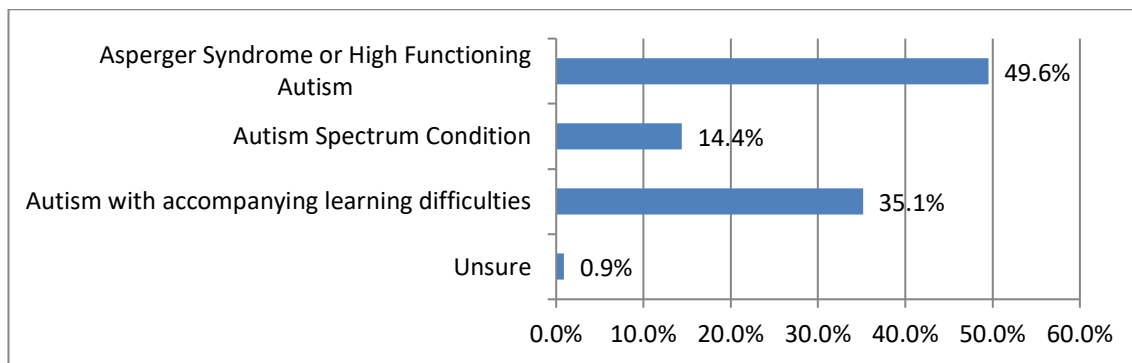
#### 5. Is your person (or if this is you) male or female?

Answered: 111 Skipped: 0 (compulsory question)



#### 6. How would you describe the level of autism? How would you describe yourself if this you?

Answered: 111 Skipped: 0

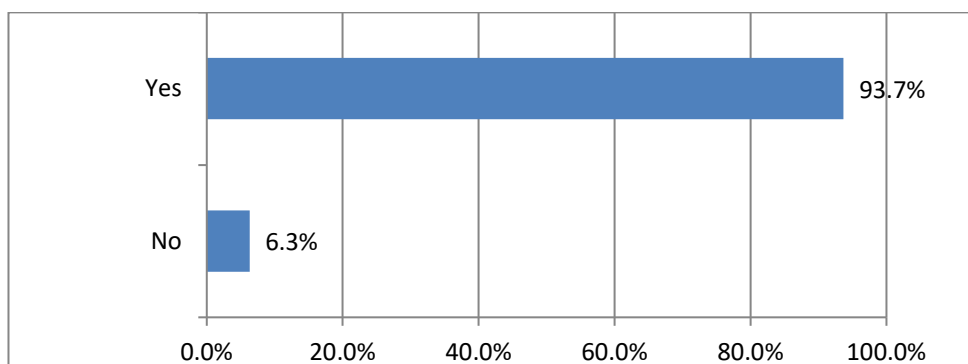


Other responses:

- Classic autism Levels 2/3
- High functioning autism with learning difficulties
- I support 2 people with different levels. Ages above also 18-25
- All forms over the range of people that I work with
- PDA
- Autism with associated anxiety and depression
- with other psychotic conditions

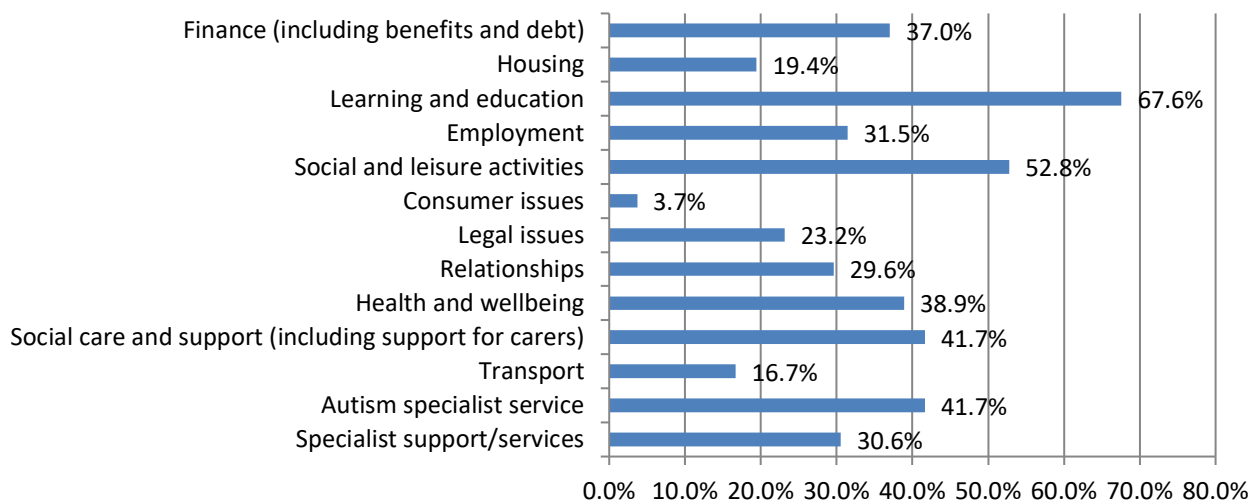
## 7. Does the person concerned (or if this is you) have a formal diagnosis of autism/Asperger syndrome?

Answered: 111 Skipped: 0 (compulsory question)



## 8. What sort of things might you need advice about at the moment? Please tick as many boxes as you wish.

Answered: 108 Skipped: 3

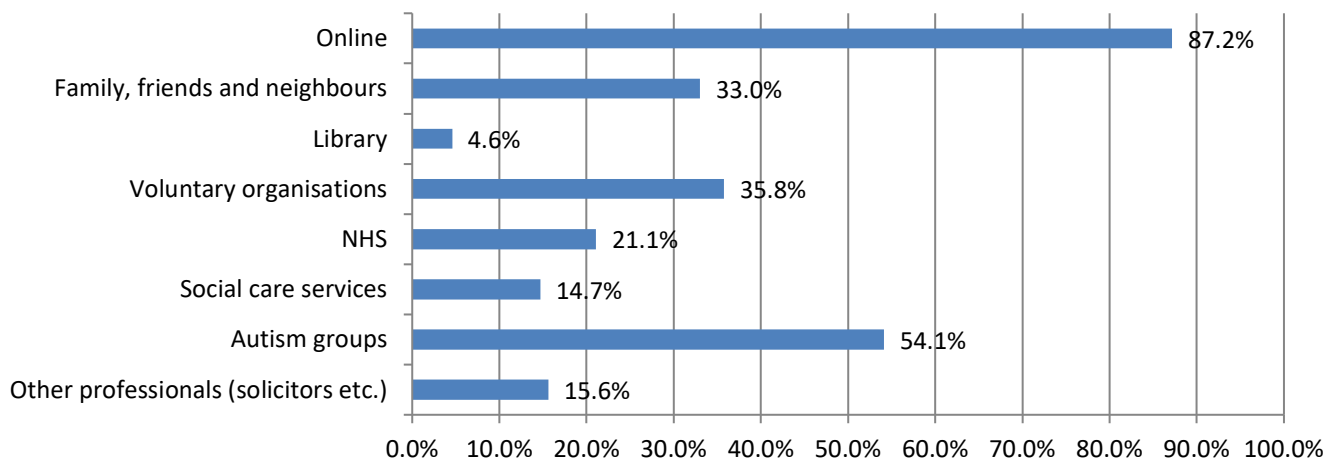


Other responses:

- 1:1 for travel (out of area). Help when in crisis. Sometimes 1:1 like Jamie (Lion) gets. But I thought too bright. When in crisis exactly same, walk in traffic, near deep water, go non-verbal - not safe. Hard luck though as look normal and don't have an LD so don't get help where I need HIGH level help to keep safe in crisis.
- How to spend the rest of my life away from neurotypicals
- Trained counsellor for teenagers with suicidal ideation
- Moving home and helping with anxiety
- Mental Health

**9. Where are you most likely to go get information and advice? Please tick the TOP 3 places you are most likely to go for help?**

*Answered: 109 Skipped: 2*



Other responses:

- ADRC
- Day service
- She falls between all these
- Specialist Teacher Advisory Service
- sendiass
- IPSEA
- Previous school and college
- Getting help almost impossible

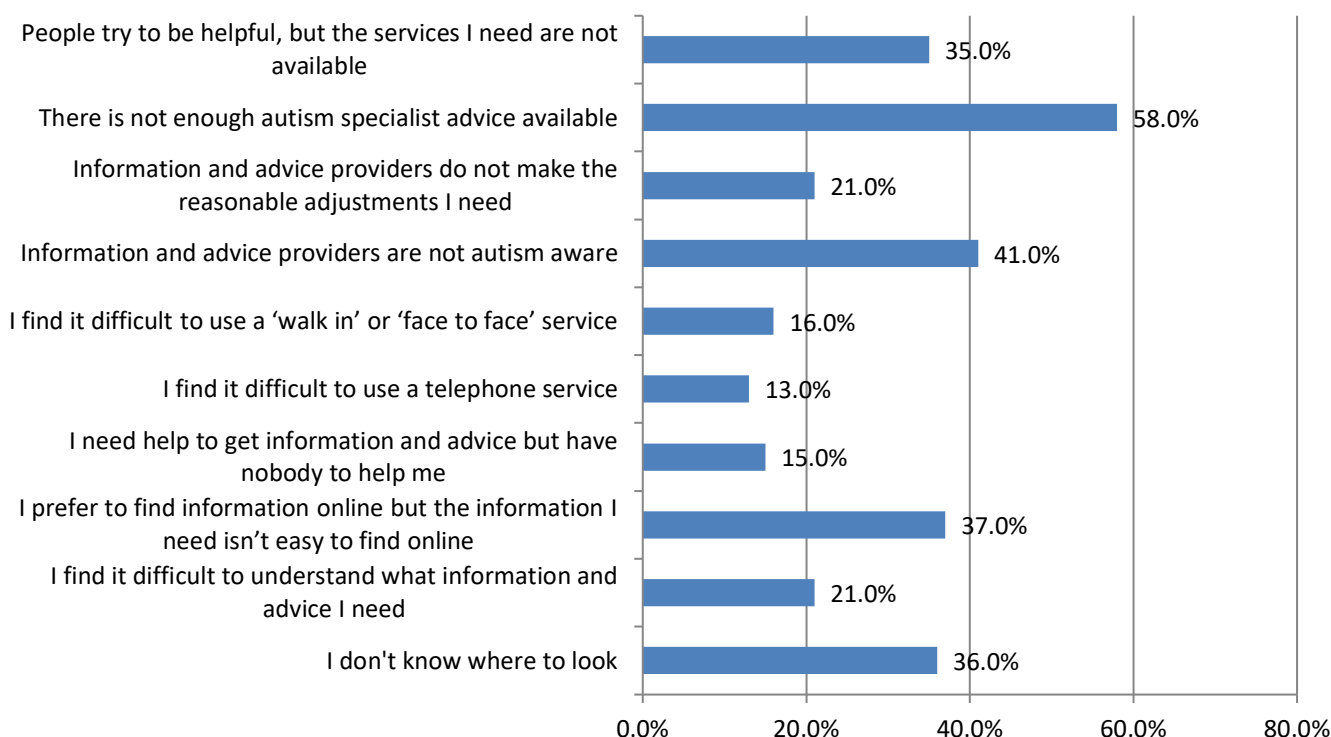
**10. What sort of things make it easy for you to get the information and advice you need? This is a very open question. Please answer it in whatever way you like. Your answer might include comments about: knowledge (such as being aware of places to go for help), or practicalities (such as having transport), or feelings (such as being confident).**

*Answered: 85 Skipped: 26*

See Appendix 1 for all responses.

## 11. What sort of things make it difficult for you to get the information and advice you need? Tick all that apply.

Answered: 100 Skipped: 11



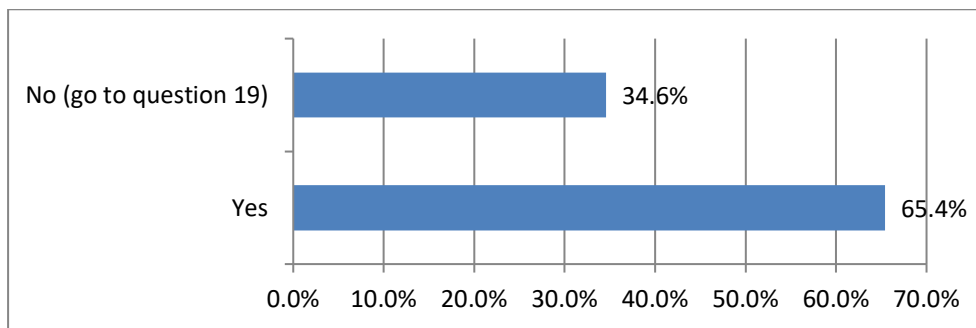
Other responses:

- Too much reliance on internet
- Neuro-Typicals
- It's just random personal recommendations, following leads from one person to the next, asking lots of questions. I wouldn't know where to go "officially".
- As above
- Since our NHS has been privatised, we have lost our paediatrician - having NHS support would be ideal from professionals. Being sent to voluntary organisations is not good enough.
- not always available e.g. mentoring young people with Aspergers into a job
- I feel it's such a battle getting the help because of funding cuts
- I work full time and services are not available out of hours
- Nothing in Winchester for young adults 19 to 21
- Neurotypicals
- too tired to cope with research and going to new places to find out things
- Moving regularly and not having one point of contact in new places
- School don't follow advice
- There is not enough help and support for adults with ASD and additional mental health needs.
- My son's children's services case worker got made redundant. New case worker useless. Camhs case worker useless and wrong. 2nd case worker left, not been replaced, so the services we need are not available (no one is helpful!)
- Schools do not have enough awareness of sensory issues
- Most things I find are private and not done by NHS or I don't meet criteria for things job centre was no help once one of my sons was put in support group and he didn't fit criteria from social
- Most available support is only available during the working day.

## 12. It would really help us if you could recall an occasion when you received information or advice. Can you think of an example to tell us about?

Answered: 107 Skipped: 4





### 13. Where did you go for help?

Answered: 69 Skipped: 42

See Appendix 2 – Specific Example.

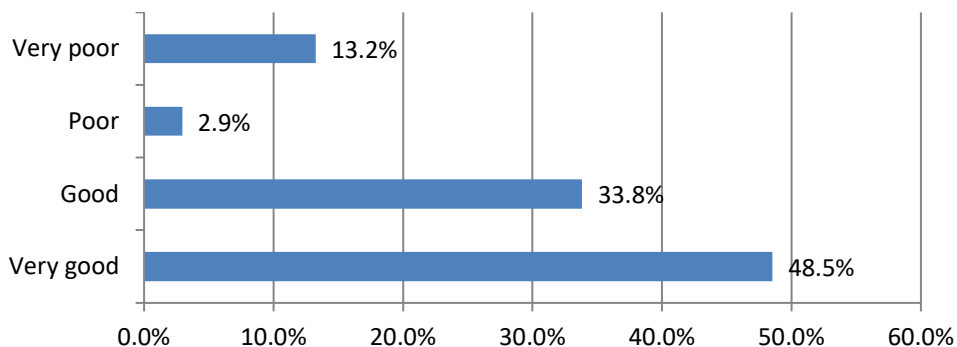
### 14. What made you go there? This question is about how you found your way to the service, whether it was suggested to you by someone else or you found out about it online etc.

Answered: 68 Skipped: 43

See Appendix 2 – Specific Example.

### 15. Thinking of that service, how would rate it?

Answered: 68 Skipped: 43



### 16. Why?

Answered: 65 Skipped: 46

See Appendix 2 – Specific Example.

### 17. What difference did getting this help make?

Answered: 62 Skipped: 49

See Appendix 2 – Specific Example.

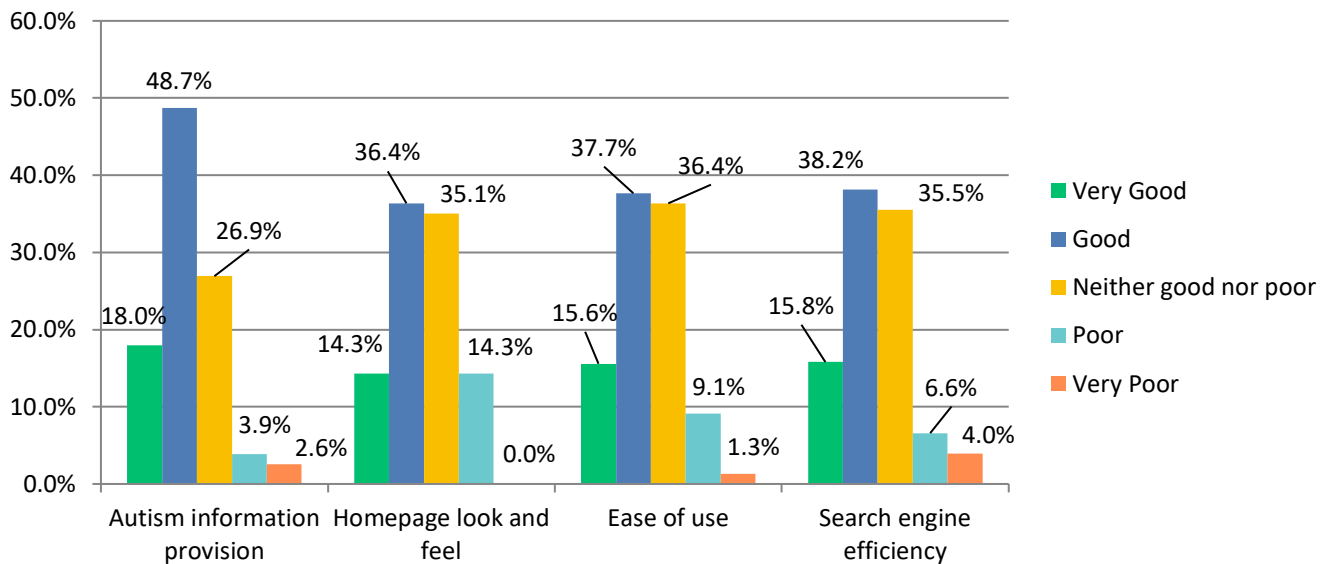
### 18. Any other comment about that experience?

Answered: 32 Skipped: 79

See Appendix 2 – Specific Example.

### 19. Please rate the Local Autism Directory for the following:

Answered: 79 Skipped: 32



## 20. What did you like about the LAD?

Answered: 77 Skipped: 34

See Appendix 1 for all responses.

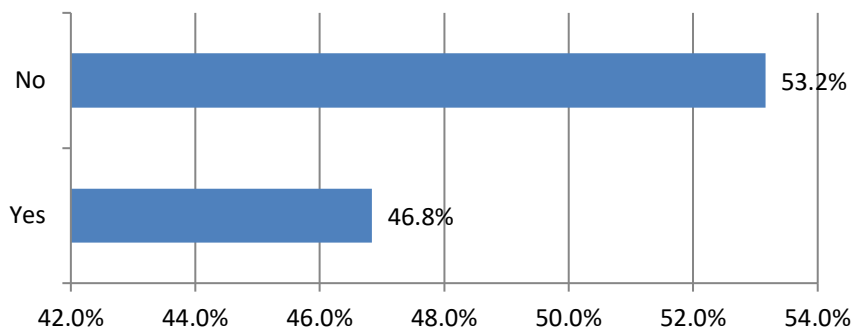
## 21. What do you think needs to be improved?

Answered: 77 Skipped: 34

See Appendix 1 for all responses.

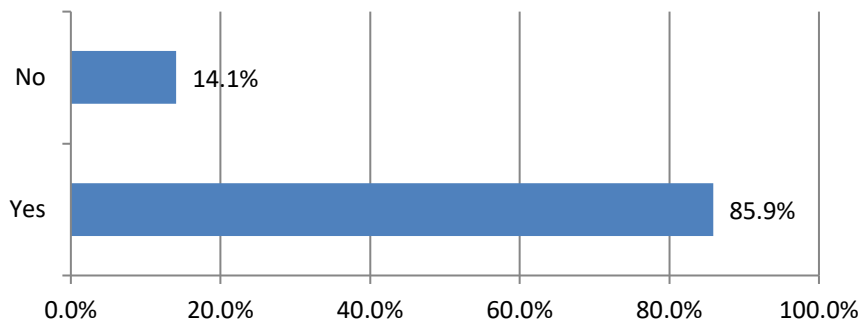
## 22. Have you ever used the LAD prior to filling in this survey?

Answered: 79 Skipped: 32



## 23. Would you use the LAD again? Please give reasons for your answer.

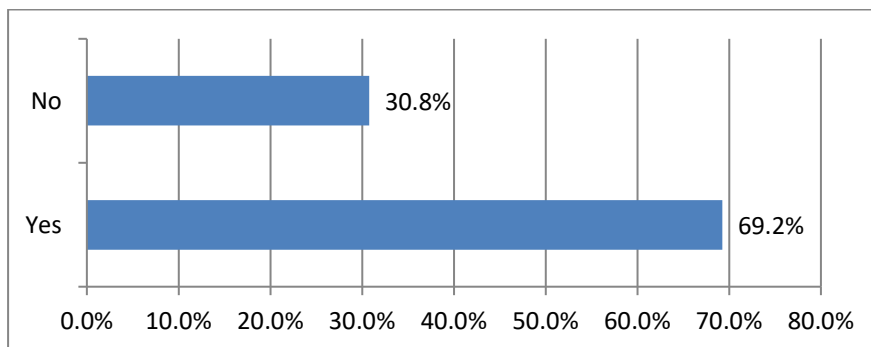
Answered: 78 Skipped: 33



See Appendix 1 for all responses.

#### 24. Did you find the directory useful? Please give reasons for your answer.

Answered: 78 Skipped: 33



See Appendix 1 for all responses.

#### 25. What is your postcode? (optional) This will help us to understand how well our survey is covering different areas within Hampshire

Answered: 73 Skipped: 38

#### 26. How did you hear about this survey? (optional)

Answered: 71 Skipped: 40

### Appendix 1 – Full responses to open-ended questions

**Question 10 - What sort of things make it easy for you to get the information and advice you need? This is a very open question. Please answer it in whatever way you like. Your answer might include comments about: knowledge (such as being aware of places to go for help), or practicalities (such as having transport), or feelings (such as being confident).**

Nothing - don't like asking as I always bad, get put into constant overload by unnecessary triggers. I am always put at risk - then no care available as I don't have a LD!

Knowing who or where to ask, knowing other families who also have children with Autism. Being confident and having acceptance of child's Autism.

I am not aware of any charity or professional support in Winchester. It feels like parents are left to fend for themselves in this area. There is an expectation that we should commute to Southampton which is not practical for most people.

Please can you set up more things in Winchester.

I have gained a lot of support from the Inclusion Manager at my daughter's school of parents/carers support groups locally & also of a cygnet 12 week parenting course run by Barnardos which I have enrolled upon.

People that understand the way she communicates.

so things can be addressed in a way that she understands

I am an Autism Ambassador for Hampshire so I would use my contacts

Talking to other parents

Information via the internet

Links to autism specific organisations

Clearer information on where to go for help, particularly for an adult with autism. Once an autistic person reaches adulthood there is little or no help on offer at all. This is a violation of their human rights and needs addressing forthwith.

Talking to professionals and talking to other parents who have children on the spectrum. Going to groups and being given leaflets

My experience so far is that I find information by chance or word of mouth. Central signpost service is useless and just takes me round in circles. I get frustrated and upset because no one person seems to be able to help.

Emails direct to my inbox

Autism websites. Support group.

Having the information online.

Its very hard to get the information you need. There is very little support out there if you are a parent of a child with autism

As I am a Senco for a Pre school I have a good amount of knowledge in this field in early years and therefore can apply this to my own situation with my Son, however as he becomes older I have more concerns about his learning and the fact that he is heading towards taking GCSE exams. He is very bright , but finds recording tricky, and due to his anxieties he finds staying in class very difficult in some subjects for some topic areas. Wondering why he needs to take GCSE exams and not functional skills tests, and also would be really interested in the voice activated system to record his answers for his exam questions

Access on the internet and by telephone and also more local availability.

I get information from professionals such as Ed Psychs which I have employed. I also get information from the excellent Consultant at the Maudsley that my GP referred me to on request. Finding leads to good professionals tends to be "random" eg meeting someone at a party who recommends someone from their personal experience. I also get a lot of knowledge by being the governor of a special needs school (not my son's).

Networking with professionals and others who have found help.

The County Council Young Adult 18-25 did not want to know or respond. My daughter now has severe body dysmorphia and anorexia directly precipitated by her emotional experiences at school as high-functioning ASD.

I work full time so it's difficult to access support groups.

I use online support groups and access professions or autism hampshire for specific issues

To go to a specific website or service.

Services I can call and speak directly to

places that you can drop into, and are easy to get to.

Information all in one reliable place - ie local offer website

Signposting from websites to others"

Available free online

Access to services via e-mail or on-line, as time is limited.

Joined up thinking - linking education and health would help. Online up to date information. professionals available such as paediatricians. Educational opportunities - people supporting schools and training for teachers.

High quality websites with good navigation and links

It's easy to get information, the problem is the help you need isn't usually available so the information is pointless as all it does is tell you what should happen, which doesn't match with the reality of what will happen.

As well as accessing the information on a computer, being able to talk to a person if I have further questions which are not answered on various web sites.

clear websites well easily labelled links

Online

Its not easy, most services are aimed at autistic children, and finding help for adults is difficult

Knowing where to go to get the information

Accessibility - long, long waiting lists.

Practicality and confidence. My son is going through a period of school refusal and so I can't make it to daytime groups and evenings are out because I'm a lone parent. Confidence is an issue due to depression and previous bad experience with support groups

find out most things on line

Information and advice is NOT always easy to find out in the community, hence going online is usually easier.

Getting more info from sons school more support groups or more groups that offer leisure activities

I don't really know where to access help other than online or through my gp

Ability to search the internet and social media for advise and guidance.

Out of hours telephone support , evenings and weekends.

Online support with FAQ's

Social media

Special needs jungle & Mighty

Local friendly support groups

support hub web site would be great to direct you in the right place to go to next  
via other parents

youth club  
 college  
 school"  
 Hampshire Autism  
 Asperger Support Group Southampton  
 the increase in acceptance and knowledge around the condition, which had led to more pathways top take for  
 information and ideas  
 Online information is so much more helpful because it doesn't involve talking to anyone or going anywhere strange. The  
 child needs me to advocate for them if official information is needed.  
 Network friends social groups in similar circumstances  
 There is nothing that makes this easy in Eastleigh. There is NO support from social services who just give us the run  
 around and make us wait for months on end and then do nothing.  
 No support or contact from mental health services. We're just expected to go through the GP, which also takes months.  
 It's just a total joke when someone transitions from adolescent to adult, you're dropped like a stone and WE have to run  
 around BEGGING services to help us, and they just keep passing you on someone else."  
 being able to ask by email although many orgnaisations dont reply  
 If there was a common website that help in getting all relevant informations. A common local services directory with all  
 information  
 when people are patient and accepting  
 when information is brief and bullet pointed  
 when instructions are illustrated  
 when i feel safe and like it is ok to ask for help, rather than being expected to know what to do or how to do something  
 when things are located where they say they are and happen when they say they will"  
 time to research. availability of information outside of working hours.  
 A website which is easy to navigate and has a very good search facility. Also promotion in partnership with the  
 Hampshire LD Partnership Board  
 Nothing really!  
 Flexible opening times  
 Having a central place that can signpost to right area  
 Being confident enough to seek things out"  
 I've only found out my son autism at easter. And feel after that I wasn't given help or advice or where I could go I hadn't  
 to found out myself.  
 I've found it quite difficult at times as there's a huge amount of advice for education and for those who are under 16 but  
 there is not so much information for adults. The information available is very general and there is very little support. I  
 know of one young man who was being visited by SAIL who was then discharged because they felt his goals were not  
 achievable but they didn't even bother to write or telephone, they just didn't bother turning up.  
 Using email so not restricted by time or children but I don't always get replies by email  
 I am a parent/carer and also work in special needs, I find a lot of information out through my work, I also attend most of  
 my sons meetings with his care coordinator.  
 Access to a range of information online and networking with other people who work to support those with additional  
 needs  
 A conviction that if I don't find the answers and advocate for my children no one else will. "  
 I have no idea,  
 So far nothing has been/is easy :-(""  
 Knowing where to go for help  
 Being able to email, I cannot use a phone so if you are only able to phone that place is not accessible for me.  
 Parent Voice  
 NAS South Hampshire Autism Branch  
 IPSEA  
 Support4send  
 Hampshire Autism Voice  
 Hampshire Parent Carer Network"  
 Confidence in recognising there is a great need and that I am not overreacting. Trusting others.  
 Advice being closer (Whiteley is too far when you only have a bicycle)"  
 Having a social worker who understands our points of view as parents, that we are working in the best interest of our  
 adult son. That they can listen to us and our son, as well as other professionals.  
 Knowledge (such as being aware of places to go for help)  
 Joining Autism groups and receiving regular e-mails and information on-line.  
 Knowing the information is up to date  
 All you get is obstacles when you try to find information. There is nothing in the Hampshire for parents of autistic  
 children to get help / support for their children  
 Good sign posting via the internet

Facebook groups as often stuck at home.  
 Speaking to others in same situation.  
 Having support and knowledge  
 Easy to use websites aimed at young adults  
 Using a smartphone / app  
 Sometimes its very difficult to get the help you need, especially mental health issues, anxiety.  
 Use of search engines. Good links with autism specific school and specialist college (albeit neither in Hampshire).  
 Member of number of organisations that circulate regular SEN information e.g Parent Voice  
 Knowing someone you trust you can go to for guidance such as a good school senco  
 There seems to be nowhere that I can get help for my son  
 Everywhere we go we are turned away  
 He is unable to survive in his current position. If we were not here he would be living on the streets.  
 Knowledge that there are actually services out there that can have something real to offer.  
 I know were to find things just don't know what's best to meet need  
 If I can access online what I am looking for that is best for me, as I find using emails means I have a 'paper trail', plus I can handle things in the evenings when all is less hectic for me.  
 being able to access online information and get specific answers to specific questions. so much advice is very specific for autism but so many children, my son included have co-morbid conditions and there seems to be a lack of knowledge about this within autism organisations  
 Friends who have gone through this before can help. Going to events to talk to autism charities/CAHMS stall helps too.

## Question 20 - What did you like about the LAD?

You could find things.  
 I like the list of support that's there & all the contact info. By the way gambados can be deleted - partyman is its new name and us already listed.  
 information  
 Clear & easy to navigate  
 lot of info  
 The fact it exists to pull all info in one place  
 It's searchable with keywords  
 Easy to use  
 Open stop shop for information  
 Lots of information  
 Ease of use.  
 I found a phone number to call for information but couldnt find it again.  
 It has what there is in one place  
 comprehensive  
 Lots of info including useful services for families I work with to get to know about.  
 Nothing  
 lots of varied information  
 Good  
 "Logical lay out. Search function.  
 Information all pooled in one place. "  
 Lots of information  
 "Clear text  
 Good search facility  
 Range of services listed  
 Area updates"  
 It's mainly a portal to other things  
 having a single point of access  
 I didn't like it. I'm not really sure what it's supposed to do. I found it difficult to read and I couldn't find anything on it that isn't already available somewhere else and doesn't just direct you to a different website.  
 I didnt like it - very poor  
 Too complicated  
 Wasnt helpful  
 There is some useful information  
 Good on information  
 Very easy to search for local information  
 In just a few minutes I found information I had not had before  
 Lots of information  
 easy to navigate

That it has lots of info  
 I don't know anything about LAD  
 A lot of info in 1 space  
 Simple and easy to use for searching events.  
 Lots of information  
 very good easy to use  
 NA  
 Good and efficient  
 it has a wealth of information available  
 It was full of information and organised by geographical area.  
 I haven't used it that often  
 good to see lots of information in one place  
 It gives a list of all necessary things in one place  
 blue writing  
 search by postcode and distance  
 Very comprehensive and east to use.  
 nothing stands out  
 Having things in one place  
 Easy to use  
 There is a lot of information available but only if it contains the answers to your questions  
 There is a lot of services listed  
 Research pages  
 THIS IS THE FIRST TIME I HAVE BEEN INFORMED OF ITS PUBLICATION!!  
 Fairly easy to navigate  
 N/a  
 The amount of information available  
 Lots of information  
 The Homepage and ease of access. plus having everything in one place yet segregated enough for/by definition.  
 Nice layout.  
 It was easy to use  
 Some useful information.  
 Not much  
 Easy to use  
 One place to find info  
 Easy to use  
 Search facility for local organisations  
 One stop shop approach  
 able to find local services  
 Apparently lots of services available  
 info  
 Nothing in all honesty appealed to me  
 All the information in one place

## Question 21 – What do you think needs to be improved?

n/a  
 More support in Winchester please. I couldn't see anything in LAD for Winchester  
 nothing  
 N/A  
 not sure  
 The home page is far too busy and cluttered: it put me off and I am not on the spectrum: possibly more graphics rather than so much text  
 What do you do if you can't find what you're looking for?  
 Not sure  
 Page layout - it is a bit cluttered and it's difficult to focus on what you need  
 Solicitor lists. Most solicitors I have contacted, including those on the NAS website, that offer specialist Autism representation, will only help if you are prepared to pay them lots. Otherwise the doors close. They advertise themselves but seem to really be placing themselves on the list to fish for business. At surface level, they advertise themselves and are casually believed by admin who compile the list out of good faith. But when it came to it and I required serious help, none of the A-Z listed solicitors would help.  
 N/a

It needs to be more comprehensive and less "random". I searched on Education, nothing came up. (I would have expected a list of schools with autism provision at least - it forced me to put a geographical radius in too which seemed a bit irrelevant). I looked at the Winchester support group and learnt about a cinema outing from Feb 2016. There were columns of text on the right of some pages that had nothing to do with the main subject of the page. It was text heavy in places. It should be clearly organised under different headings along the autism "customer journey" ie diagnosis, where to go/how to get, post diagnosis, what next, health support, educational support (primary, secondary, tertiary etc), transition, training/work options etc etc, adult services, who to contact for information.

It didn't actually have anything that would help us.

needs a lot of comprehension and navigation

none

More variety and up to date

Don't know

I got pop-ups that blocked content with every click.

The homepage is very text heavy, which could be a problem for some people. Could more pictures/buttons be used?"

Difficult to find things to help with our particular needs my son needs a lot of support and I have chronic fatigue  
nothing

The look of it is dated and there are better ways to organise data

More specific info relevant isle of Wight although acknowledge this often due to lack of services available

I don't really understand the point of it anyway? All the information I could find on it is already available in other places.

links to what I ask for - PIP appeal - nothing of immediate use.

Too complicated

More info for adults with ASD

Need to spend more time on it to be able to say. Lots of information but seemed a bit confusing

Wrong end of county - need practical support locally, need practical provision in education

Nothing I can think of

Nothing

Nothing

appearance. more info on groups for Parents/carers.

No improvement to website

I don't know as this is the first time I've heard of it.

There is too much in the first page and not well designed

Nothing.

More people need to know about it

nothing all good

NA

Cannot think of anything, except endless lists of Solicitors proclaiming to support Autism, but when you approach them, unless you have money to pay their substantial fees then they tell you that they cannot help you. Most on the list are there simply as another source of drawing in customers. They are not checked for authenticity as each administration board will blindly take their surface advertising at face value and include them in the list. This is a major problem whenever I have attempted to access solicitor help. Autism websites such as NAS have extensive solicitor lists, but when you actually trawl through them and contact each solicitor in turn, like I have tried, you come up against a wall. They are not interested unless you have copious amounts of money to burn.

n.a

Is the blue type the best? It is not the easiest colour for me to read for a while.

the site isn't very appealing and doesn't come up on google searches

More activities around Hart and Rushmore

smaller chunks of writing

Needs to be more intelligent - came back with Portsmouth services when we live in Hampshire so couldn't access these.

Front page is very busy and text heavy.

Nothing, it's fine

its very nondescript

Far too wordy, hard to find what you need

Nothing

Much more advice for adults in areas outside the main towns our cities.

More information about services offered

Look and feel - there is a lot of text and the odd random unrelated picture.

As with many of these things there needs to be more providers listed and information added as neither of my searches produced results. I'm aware of the feedback facility and will use it.

I have already seen this before but there is no information about youth education for people with Asperger who cannot attend school, which is what I so desperately need help with.

Needs simplifying visually

Homepage (on an iPhone at least) looks very basic and cluttered



Content. More information across the board with defining filters for ease of use.  
 More services & opportunities for young adults.  
 It highlights there are massive gaps in provision in my area.  
 More links to relevant websites.  
 Not user friendly. Too much information / appears cramped  
 Information about benefits that can be claimed inc unemployment and support for claiming  
 More tailored to area  
 Make it look better on mobile devices  
 Not sure  
 Some of search links do not work that well e.g. search for education in all areas only gives portage whereas search for just Hampshire brings up a lot more. Former should show everything that is available in area. Would be good to also include certain information on adjoining counties for those who live close to county boundaries. We are close to Surrey and have accessed services (mainly respite) there  
 made easier to read and search details to remain on the side bar making it easier to do a second search  
 I have heard or contacted most of the relevant services but none can help us  
 not sure  
 Search engine is clunky and not user friendly, webpage isn't encouraging and again not user friendly  
 Provision in East Hampshire!

## **Question 22 - Have you ever used the LAD prior to filling in this survey?**

Thought it was just a list of autism sites like AH or NAS which I use anyway.  
 Didn't find anything for Winchester  
 Didn't know what it was useful for  
 Never occurred to me.  
 Unaware of it despite being a NAS supporter  
 Because it was too vague  
 I wasn't aware it existed  
 Never heard of it before.  
 is it new or just not often advertised or not much good?  
 Didn't know about it  
 Didn't know about it  
 Wasn't aware of it  
 Did not know about it  
 Didn't know it existed  
 Unaware of it.  
 I didn't know about it.  
 Didn't know it existed!  
 Always presume there will be no answer to my enquiry  
 Was unaware of the sight  
 Didn't know about it  
 WAS UNAWARE OF ITS EXISTENCE!!!!  
 Didn't know it existed  
 I never knew it existed  
 Wasn't aware of it  
 Didn't know about it  
 trying to find information on volunteering  
 Not aware of  
 Didn't know about it  
 Not aware of it.  
 Wasn't aware it exists

## **Question 23 – Would you use the LAD again?**

Will look up  
 It needs some entries for Winchester  
 to find answers to give others information  
 It's quick and easy  
 As above - content is "random". I would get more comprehensive information by going directly to a professional eg Ed Psych re Education or by googling key words.  
 I tend to look for things using a search engine  
 It would help me find out about services that I could recommend to parents

I didn't find anything on it that I hadn't already seen on other websites.  
 only if nowhere else to go and I doubt I'll remember it as it was quite poor.  
 Need to get any help and advice that we can  
 go through the information provided properly  
 Good to be able to narrow down the options when looking for information  
 Useful information  
 if info required  
 Id like to find out more  
 if looking for service  
 Useful information  
 It looks helpful.  
 Good at finding relevant information  
 to check if anything new  
 I would give it a go now I know it's there  
 As it will help others  
 I will remain optimistic that services will improve  
 May be useful in the future  
 as above  
 The data it does hold is helpful.  
 If there was a specific topic shared on Facebook. I wouldn't actively search this site specifically  
 If needed I would use it to find out where I can get information  
 It has several different categories of useful information  
 It was quick and easy  
 Good source of information  
 It is helpful  
 possibly use again  
 If requiring information on social services - see response below  
 Will go and use it now  
 I didn't like it, so would probably go elsewhere  
 maybe

#### **Question 24 – Did you find the directory useful?**

Looked up Hampshire things. It's ok as long as have a LD as well.  
 It needs some entries for Winchester  
 i did not know where to look for things  
 It is useful to have one stop shop  
 Saves having to search the internet  
 Good information  
 I think I have already answered this.  
 We did not meet the criteria for any of the organisations we were signposted to.  
 My daughter needs to use it but is resistant to need.  
 Good information  
 Good range of services that parents might need  
 See above  
 Too complicated  
 Need to spend more time looking at it,  
 Not yet  
 Found details of groups I never knew about  
 Great to have all the information/links in one place  
 some use in finding support groups.  
 Discovered group in Alton that I would like to use  
 I haven't used it yet.  
 It is always helpful to discover SEN friendly activities and events.  
 Useful information  
 it doesn't have information on PDA; couldn't find any information on anxiety or mental health  
 To find local activities  
 no groups near enough to me  
 Lots in one place  
 Not looking for anything specific but it's far too wordy  
 Yes very useful  
 Not really answering my query.

Contact details for a lot of different services

As above

As above.

If looking for where to find information I would find it very useful

Because it attempts to have everything that is required in one place.

Too generalised for Hampshire needs to be more borough specific.

It was simple and straightforward

found an organisation that i wasn't aware of before

Limited by the fact our young adult with autism lives in Surrey but is funded by Hampshire but looks excellent resource for those resident in Hampshire

Although as above

Didn't have what was looking for /needed in area other than what Already tried

Hard to search for what I wanted

No provision in East Hampshire

## **Question 26 – How did you hear about this survey?**

Sent by HAV

Email

WORK

via Hampshire Voice e mail

Facebook

Emailed as an Autism Ambassador

email

Received an email.

email

Emailed

Received email

Via email

Google

sent to me

On line

Parent voice email

via e-mail from Vanessa Cosby, after attending Autism Ambassador course.

Facebook

email autism ambassador

Post on Facebook from Hampshire Parent Voice

email

Facebook

email

Via my sons school

FB

Facebook

email

Facebook

Parent voice

Facebook - Autism Voice

Facebook via Parent Voice

Parentvoice

parent/ carer email

email

email

It was emailed to me

Email request.

E-mail

facebook

From my friend

Facebook

Parent Voice bulletin

From HAV

emailed to me

Facebook

Autism uk  
Email  
Email  
Support group Facebook page  
emailed  
HAV Facebook page  
Facebook  
On a local Facebook support group  
Email from Vanessa Cosby  
You e-mailed.  
facebook  
Mailing list.  
Through Autism Hampshire's Facebook page  
E-mail sent to me with survey.  
Email  
Email  
NAS local group email  
South Hants National Autistic Society newsletter  
NAS South Hampshire email  
via email  
e-mail  
E mail  
Via email  
emailed from HAV  
Email  
Email

## **Appendix 2 – Specific Examples (Questions 12 to 18)**

Respondent #	Where did you go for help?	What made you go there? This question is about how you found your way to the service, whether it was suggested to you by someone else or you found out about it online etc..	Thinking of that service, how would rate it?	Why?	What difference did getting this help make?	Any other comment about that experience?
Respondent 1	Social - to ask for an advocate for a complaint re abusive SW. They told me to GET MY OWN.	Ombudsman told me I was entitled to one from social.	Very poor	Never happened, was refused.		BAD. I never find any advice places that actually listen to you or not aware of any.
Respondent 2	Jo Maxwell-Heron from Parent Voice	I have had advice from Jo before.	Very good	Jo is always helpful, knowledgeable, approachable and if she doesn't know the answer she knows who will.	It meant that I learnt about how my son could access funding for support at out of school activities At	
Respondent 3	I have lots of questions about how best to support Danny but I have no-one with the right knowledge, training and experience of high functioning autism to ask.	Haven't found a service to support me in Winchester	Unknown			
Respondent 4	I have gained a lot of support from the Inclusion Manager at my daughters school of parents/carers support groups locally & also of a cygnet 12 week parenting course run by Barnardos which I have enrolled upon.	Because my daughter was due to start at the School this September & she was diagnosed in January.	Good	She had a vast knowledge of working & supporting children with varying needs. She has also recently attended an Autism Ambassador course which meant she was particularly up to date regarding my daughters condition.	A huge amount. I felt less anxious for my daughters future.	
Respondent 5	the people that support me in my home. and an advocate as I do not have family	.	Good	they took time to understand	had the operation	.
Respondent 6	I attended a workshop in Portsmouth about Autism and met the lady who runs a social group in our area and signed my son up with her: this was mostly due to luck.	Motivated to find out as much as possible about services for people on AS	Good	The social group is a life saver: my son has attended every week for over 3 years since he joined: my fear is that it depends on the goodwill of the 2 stalwarts who run it and when they leave the group will dissolve	See above: it is the only purely social activity my son engages in	
Respondent 7	Conversation with mental health social worker	Referred to adult mental health by school. Psychiatrist then referred to SW	Good	Good understanding of individual needs. Put appropriate things in place. Very responsive.	The right support has helped move my son along.	All round positive experience.

Respondent #	Where did you go for help?	What made you go there? This question is about how you found your way to the service, whether it was suggested to you by someone else or you found out about it online etc..	Thinking of that service, how would rate it?	Why?	What difference did getting this help make?	Any other comment about that experience?
Respondent 8	My son went to the local Job Centre for careers advice and was treated in a very discriminatory and dismissive way. Basically told there was nothing they could do to help him.	Suggested to him by transition worker	Very poor	For reasons stated above	None, as there was no help!	Job Centres need to offer more help to people with additional needs
Respondent 9	Both my sons schools advised me to go to autism Hampshire and camhs referred me to banardos autism course.	I have not done the autism course yet but autism Hampshire have been very helpful	Very good	You can access information online there is always someone to call for help		
Respondent 10	Citizens Advice	Always been aware of local branch of CAB	Good	They have helped whenever they have been able to.	CAB were able to resolved an issue that had made me very unwell.	I was lost as to what to do and CAB itemised and did everything necessary.
Respondent 11	My son's SENCO. She was great- lots of helpful information, a lot of it from Autism Hampshire.	She knows my son and is keen to support us.	Very good	Compassion and willing to work with us to try new approaches.	Gave us more confidence that we could help our son.	
Respondent 12	From my sons school	Ease	Good	At the time the member of staff was very knowledgeable - she has now sadly left teaching !!		
Respondent 13	NAS	Knew about the NAS benefits help line so contacted them.	Very good	They can back to me quickly and arranged a telephone call. It resulted in getting the information we needed and the support put in place for my sons benefits to continue while he was in supported work.	Benefits maintained.	

Respondent #	Where did you go for help?	What made you go there? This question is about how you found your way to the service, whether it was suggested to you by someone else or you found out about it online etc..	Thinking of that service, how would rate it?	Why?	What difference did getting this help make?	Any other comment about that experience?
Respondent 14	I went to the Maudsley hospital in London to the CIPP team. Recommended by someone I met at a party with an autistic son. It has transformed my life and made school possible for my son. My GP had never heard of them but was happy to refer luckily. I have recommended them to others in the same situation and their GP's have refused to refer so they are left struggling with behavioural problems that CAMHS are unable to deal with.	As above - recommendation from someone I met by chance who was married to a Consultant so had inside knowledge of NHS services.	Very good	AMAZING. They listen, they do really thorough 360 degree evaluation through long detailed online questionnaires filled in by child, parent + school so that they have clear information + a picture of behavioural patterns and issues before you arrive for the appointment. 4 professionals spend at least 2 hours with the child initially checking the diagnosis and PROPERLY observing/asking questions and there are usually 2 or 3 professionals in each appointment. (CAMHS had discharged my son and said he didn't have any anxiety/OCD etc. etc. all of which are now being treated). They follow up on the phone to check response to medication, you can email them directly and they respond!!!!!! They are AMAZING.	My son's behaviour is now under control, he can concentrate at school, he is learning, he is FAR easier to live with. His OCD/anxiety/depression/ADHD are all far more	This should be available to everyone, not just articulate educated Mums that meet the right people and professionals don't argue with. I have had this experience again and again. My son is in a Residential Special Needs school and initially I was told by the SENCO in the mainstream primary that he was in that he didn't even qualify for a Statement because autism was a "high incidence" condition. The really sad thing is that some people listen to this rubbish and don't get what they need.
Respondent 15	We needed support to move my son from education into employment. We were signposted to Autism Hampshire who signposted us to their directory signposted us to two providers who each signposted us back to Autism Hampshire. I hate "signposting", everyone says they "signpost" and no one actually provides the help - they are all too busy signposting us round in circles.	We "signposted" and desperate.	Very poor	No di anything other than signpost.	We didn't actually get any help. It was really frustrating. The signposting "help" we got resulted in my taking antidepressants.	Not really- there is no help.
Respondent 16	Hants County Council Young Adult in relation to her tertiary education and failure of Sparsholt to note and respond to the Section 139a Statement	Desperation	Good	in seeking to repair the damage	as above	in longer term wasn't sufficient.



Respondent #	Where did you go for help?	What made you go there? This question is about how you found your way to the service, whether it was suggested to you by someone else or you found out about it online etc..	Thinking of that service, how would rate it?	Why?	What difference did getting this help make?	Any other comment about that experience?
Respondent 17	SENCO at school	Education issue	Good	Problem not yet resolved. Issues tend to take time to resolve	It hasn't yet	As above
Respondent 18	Autism Hampshire community access	Great reputation	Very good	Excellent service	Support and direction	
Respondent 19	Autism Hampshire course	wanted advice on dealing with challenging behaviour	Very good	Really helped to understand how to respond to a meltdown	Helped me feel calm when dealing with a meltdown	
Respondent 20	Had drive yatley	Free courses	Very good		Made me understand lot	
Respondent 21	emailed someone from autism hampshire	didn't know where else to go, someone recommended them.	Very poor	because they didn't really help me much	none.x	
Respondent 22	the college my son attends - education does seem to be more switched on compared to when he was in primary school level education	support - pastoral support/care	Very good	very aware and attentive	reassurance and we were all 'heard'. we felt understood and we trusted the establishment	very good
Respondent 23	I wanted to find a driving instructor who had experience of teaching autistic learner drivers. I tried the Local Offer website, as well as contacting several driving instructors independently. I ended up contacting the Local Offer website co-ordinator in person who did her very best to help, and provided me with as much information as she had. She also contacted some local autistic support groups on my behalf. However it seems we had identified a bit of a gap in the market, and I eventually secured an instructor with some relevant experience just by trial and error. This was very time consuming and I had to share information about my son with several people along the way, just to get to this point.	I knew about the Local Offer website through my work.	Good	The information is all in a central trusted place and the co-ordinator was very helpful.	limited, as explained in Q13 above because the website didn't have the information I was looking for.	

Respondent #	Where did you go for help?	What made you go there? This question is about how you found your way to the service, whether it was suggested to you by someone else or you found out about it online etc..	Thinking of that service, how would rate it?	Why?	What difference did getting this help make?	Any other comment about that experience?
Respondent 24	Spoke to SAIL at Gosport job centre	Social services recommended I talk to them	Very good	They were very helpful and currently someone from that charity works with my son weekly	They recommended I only felt with one set of paperwork at a time which helped me be less overwhelmed by all the papers I had to fill in for him . One of their staff is helping him with life skills I cannot help him with . Accessing public transport ,cooking from scratch	It's been very helpful for both of us because I also get to talk to another adult to help me work out how to help my son
Respondent 25	Support for Send	SEN dept. at Hampshire taking 6 months to deal with our EHCP request (when there is a 6 weeks limit)	Good	Helpful and good information	Helped us know our rights	No
Respondent 26	SENDIASS	When trying to obtain a post 16 residential autism specific placement.	Very good	quick responses, supportive and accurate information given. Sound understanding of legal perspective	Secured residential school place	
Respondent 27	NAS - PIP appeal	NAS very good	Very good	easy to navigate web site and useful info.	hopefully lots	
Respondent 28	Health visitor	2 year assessment	Very good	They actually picked up on developmental delays which triggered referrals	Just meant I was able to get support in education	
Respondent 29	We attending a Parent Voice event in Yately where we spoke to several people who gave us advice.	We were told about the event via Support for Send	Good	They have been very helpful with our EHCP application	Made our EHCP application better and have more knowledge of the application process	
Respondent 30	Mustard Seed Autism Trust	Advice from CAMHS and Parent Partnership	Very good	Explained, provided workshops	Information	All good
Respondent 31	Autism Ambassador in the police, through NAS contact	NAS contact	Good	Understood situation and Autism	Felt supported and relieved	
Respondent 32	Open day in Petersfield received advice	Knew it was happening through online ads	Very good			
Respondent 33	Camhs	My daughter finds it difficult to socialise and control her emotions e.g. she gets angry and has self harmed in the past. She also needs help with living skills	Very poor	They did nothing to help us except give us information sheets despite 12 sessions with them where they asked questions about my daughters situation but no therapies etc. were offered. They said that my daughters autism wasn't mental health so they couldn't help us.	nothing at all.	It was a complete waste of time and I think it was down to a lack of funding really.

Respondent #	Where did you go for help?	What made you go there? This question is about how you found your way to the service, whether it was suggested to you by someone else or you found out about it online etc..	Thinking of that service, how would rate it?	Why?	What difference did getting this help make?	Any other comment about that experience?
Respondent 34	Support4Send ( Support with EHCP application) IPSEA South Hants Autism Group Autism Hampshire	Education advice EHCP advice	Very good	Comprehensive specific responses	Huge difference	Would like to be able to get quicker responses. E.g. Support4Send you have to leave a voicemail and wait several days
Respondent 35	When my son was younger Parent voice was excellent ---newsletter and then on line now nothing	via another parent at school	Very good	ideal amount of information across all district so we could pick and mix but always from outside Winchester	allowed my son to socialise and visit strange places so he grew in confidence	
Respondent 36	Citizens Advice	Neurotypicals in armchair administration with absolutely no concept of the ground-base effect of their easy comfortable boardroom decisions that they congratulate each other over.	Very poor	No concept of reality because they have never personally experienced it. Yet they are so very certain of themselves.	None. My on-going campaign and correspondence involving politicians had absolutely no effect on the 'so-certain of themselves' psychopaths at Eastleigh Council.	Kill them. Neurotypical TRASH
Respondent 37	NAS website	I was originally signposted towards it by my GP and have used it ever since.	Very good	It is clear advice, it is well organised and it also signposts other places that we could get help.	Lots, along with the training that I have received in the past.	I think the NAS website is really helpful, although perhaps the amount of information might be overwhelming
Respondent 38	Local special needs group. The zone formerly NAS rushmoor.	Told by friend	Very good	Will listen . Have practical knowledge. Sign post to relevant agencies.	Access new school. Legal advice sos Sen. Social activities. Including Challengers.	Friendly
Respondent 39	South Hampshire branch of NAS	I know the chair & other committee members well.	Very good	Always there to listen and support.		
Respondent 40	No limits, Southampton, for support and advice on employment support, counselling on drug, alcohol & relationships.	The only local, adult support service available, with easy access, to get him support.	Good	He attends it, and has received support in creating a cover letter and writing a good CV. He gets counselling (according to him), but we do not know if this is helping him.	His updated CV got him a job, for a short while, and we are hoping he will use their services more to look for another job.	
Respondent 41	NAS	specialist education helpline advertised on their website	Good	helpful advice and phone back next day so not too long	ideas for EHCP and transition process - clear what we should ask for/entitled too	
Respondent 42	Got help from Gateway card services	I searched on internet to get information regarding activities for kids during school break.	Good	They had emailed me the list of activities around my area that are funded by Gateway	It made me choose the right activity for my kid and also helped me with the cost	N/A

Respondent #	Where did you go for help?	What made you go there? This question is about how you found your way to the service, whether it was suggested to you by someone else or you found out about it online etc..	Thinking of that service, how would rate it?	Why?	What difference did getting this help make?	Any other comment about that experience?
Respondent 43	Autism Hampshire office. Had lovely chat about what they offer and resourced they have available.	Was contacted by them after my details were passed on following my assessment at Thomas Lewis House	Good	Friendly people, on time, pleasant location, clear communication, patient with me	showed me more of the things I can access when I am ready	
Respondent 44	CAMHS	Had been referred previously for diagnosis, wanted further advice regarding mental health issues	Very poor	Was told that as my daughter was 17 she wouldn't reach the top of the waiting list before 18, so they wouldn't see her. She was too young to seek help from adult services.	n/a	Frustrating and soul destroying.
Respondent 45	The staff at Portsmouth University are hugely helpful with advice	My daughters university	Very good	because they listened and are knowledgeable	huge difference in her <sup>4</sup> attending university	
Respondent 46	Autism UK and Basingstoke autism hub on Facebook	Just but in autism and it came up very helpful	Very good	Very helpful and understanding	Getting my son help and support	
Respondent 47	Nas	Tried other routes	Good	Would have liked more specific advice	Helped know my rights and next steps	
Respondent 48	I asked my sons Care coordinator	I contacted the adult mental health team as my son had not been seen for some time.	Poor	The support is inconsistent, there appears to be a lack of communication between departments, they are slow and reluctant to offer help and support.	None yet... I was given the name of a company that MIGHT be able to help.	I would have liked more support and not just advice.
Respondent 49	Winchester Autism Group Hampshire Autism Society	Despair	Good	Mental deterioration , body dysmorphia and anorexia in consequence of school and college experience of bullying or ASD ignorance on part of staff.	No help to my daughter	Very difficult to find support with 18 +
Respondent 50	Autism Hampshire and Sensecare	trawling the internet	Very good	Both were instrumental in my ability to understand and better match the support I give my child to his needs.	Completely changed the way I perceived his behaviour and turned our relationship round.	Understanding the key impairments of social, communication and sensory differences was life-changing to my son and to me.

Respondent #	Where did you go for help?	What made you go there? This question is about how you found your way to the service, whether it was suggested to you by someone else or you found out about it online etc..	Thinking of that service, how would rate it?	Why?	What difference did getting this help make?	Any other comment about that experience?
Respondent 51	CAMHs,	Referred by GP after 3 years of asking for service		First case worker dismissed us subsequently advised school of wrong information. Complained to GP, referred 20 miles away to CAMHs is different location (very inconvenient). Same paperwork, same questions only to be put on a never ending waiting list for an assessment. Case worker left so no follow up or contact since February (nearly 6 months). Completely useless.	None so far... apart from feeling let down, frustrated and angry, while my sons education and life suffer further.	Waste of time!
Respondent 52	Steps 2 Wellbeing	Mental health conditions	Very poor	I was only able to use a phone to book an appointment even after walking in with my boyfriend as I'm unable to do that myself. After finally mustering up the courage to do so it took 4 calls to get through and then they double booked it and cancelled my appointment.	I was unable to obtain the advice I needed due to the inaccessibility.	
Respondent 53	Mustard Seeds	Referral	Very good	Small group work with no pressures and genuine willingness to help	Many different strategies suggested and tried. Some worked which we then followed up at home.	Brilliant
Respondent 54	I contacted support4send regarding what reasonable adjustments secondary schools should make regarding uniform. Nobody got back to me so I wrote to the head teacher. His response was that by the time my son is due to start there he thinks he will be a bit older and be fine with the uniform. My son has ASD/SPD and is always hot and only wears shorts and t-shirt all year round!	Suggested by others and on Hants website	Poor	Support4send didn't get back to me and the school seemed unwilling and had no idea about sensory issues.	No help given	



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Respondent 55	My son's School Senco. She is brilliant at her job and is very qualified, experienced and professional.	Through school.	Very good	Purely down to the individual and luck of school placement.	HUGE!!	The help, knowledge, guidance and experience provided by Mrs Greenwood (School Senco and Deputy Head has been invaluable!
Respondent 56	Learning Disability Integrated Health team		Good			
Respondent 57	Autism Hampshire	Was directed there by the assessment.	Good	They had some information, but not enough and I felt massive hurdles in helping my daughter.	It gave me confidence to advocate for my daughter.	I went to a local place, but this has now moved which makes it much harder to get to
Respondent 58	I rang Duty Social workers who put me in touch with a team who were about to carry out a review of my son's care home. I just happened to ring that time at the right time.	I didn't know what else to do. It was this of the CQC.	Good	The Social worker who was assigned to review my sons care home understood my concerns and looked into them. In the end, the local team went in to observe how the home was run and offer help in offering a better service.	We felt listen too. Our son got to go our and pursue some of his special interests, which had previously been ignored even though we had been onto them for over two years to do, and his weekly life improved.	
Respondent 59	The National Autistic Society website and I received a magazine with lots of good advice as I am a member of the NAS.	From CAMBS when my daughter was first diagnosed.	Very good	Information I need all in the same website and different links that are helpful.	A great deal as I could find information on local groups in the area my daughter could join.	
Respondent 60	Parent Voice	Reliable trustworthy and good information	Very good	Well established	Great help when I was struggling	No
Respondent 61	An IPSEA training course organised but Winchester Autism Group	Found out about it on Facebook and needed help applying for EHCP for my child who has not got a suitable school placement at the moment	Very good	Really informative and gave me confidence and skill I needed to make application.	More confidence and less stress overall. Had been not sleeping with stress and having panic attacks myself.	Great to meet other people in same boat and share ideas and know not alone.
Respondent 62	Yellow Door (formally Southampton Rape Crisis).	For counselling.	Good	They have a service called 'Diversity and Inclusion' which helps people get the support they need.	I don't know	
Respondent 63	SupportforSEND - visited stand at a meeting hosted by HPCN to meet Hampshire SEN team; might not otherwise have contacted them as thought they would not be in a position to help	See response above -	Very good	They were very helpful in providing details of a SENDIST Tribunal case that was instrumental in our obtaining an EHCP assessment. I would not have been able to find the case by myself	See response to Q16 above	

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Respondent 64	support worker at local autism unit outreach programme	a temporary headteacher at my sons school was determined to get rid of my son and wasn't following procedure in trying to discuss the matter with us or asking for a statement review.	Very good	She gave fantastic advice and advised us on the appropriate course of action	The headteacher backed down and a child that was bullying mine was finally recognised for being a bully and action was taken.	At least two headteachers I have dealt with have been woefully under/misinformed about autism and purely wanted a 'different' child out of the school
Respondent 65	Educational authority	EHCP needed	Very poor	nothing happened. 2 years later and we are still waiting	we didn't get any help yet	I want to file a complaint but don't know how.
Respondent 66	C.a.b	Knew about them	Very good	Explained things in way my son could understand	Not got outcome from this as yet	
Respondent 67	Parent Voice for EHCP help	Parent Voice used to come to the school for monthly meetings arranged by the SENCO and she encouraged me to ask for help from PV.	Very good	She helped me write up the My Story part for the EHCP, typed it all up sent to me to proof read and when circumstances changed she changed it accordingly.	My son was granted a 30 1/2 hr EHCP and subsequently been agreed he needs specialist schooling.	It met all my needs exactly and really worked for me.
Respondent 68	NAS Hampshire	Son is a member and attends lego club there	Very good	They listen and find information if it isn't readily available. The staff have autistic children and really 'getbit'	A lot.	
Respondent 69	I went to a PACE meeting organised by CAMHS in Aldershot last week.	I found out about it on Parent Voice and on Aspergers Minecraft Facebook group. I went there because it was the first time I had the opportunity to talk to somebody from CAMHS and I was interested by the talks.	Good	The talks were not as good as I was hoping but the lady on the CAHMS stall was great to bounce ideas. I also had a good chat with the lady on the Autism Hampshire stall.	I borrowed a book from Autism Hampshire about ways to calm down. The idea that CAMHS cannot help us was confirmed :-(	