

Autism Support Service for Adults

A survey of 21 questions was circulated from 06.06.16 – 29.08.16 via Survey Monkey web link relating to the need for an autism support service for adults, and gathering views about the Adult Support Service (grant-funded by Hampshire County Council and provided by Autism Hampshire between April 2014 and April 2016). A total of 89 responses were received.

Summary

This survey was aimed at adults with autism (18 and over) and their families and/or carers, or professionals that work with them. We did not receive enough responses to compile a conclusive report, therefore this is an outline and general summary of the responses we did receive. The survey was in two parts, part 1 was about the need for an autism support service for adults, and part 2 was about the Autism Support Service run by Autism Hampshire's Community Access Team.

Part 1

The need for an autism support service for adults

The majority of respondents were from Hampshire (94.4%), with the highest proportion from the Eastleigh Borough (19%), followed by New Forest District (16.5%). We had good representation from all of the other unitary authorities in Hampshire. Just over half (53.9%) of respondents were parents or carers of a person with autism, and 40% of respondents work with a person with autism.

The majority of responses concerned adults with autism who were in the 18-25 age bracket (44.9%), followed by the 26-39 age bracket (32.6%). The majority of those concerned described their autism or had it described for them as autism with accompanying learning difficulties (43.8%), followed by Asperger syndrome or high functioning autism (40.4%). Most (92.1%) had a formal diagnosis of autism.

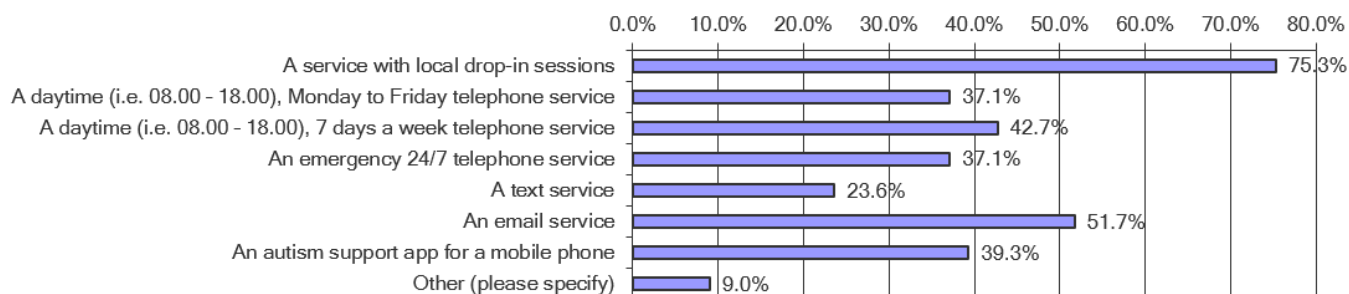
The most widely used resource for finding out information about local support services was Autism Hampshire. 13 respondents do not look for any local services or support, and 3 respondents specified that they have had no help. The resources listed in order of popularity are listed in table 1 below.

Table 1

	Response Count
Autism Hampshire	37
Other parents/word of mouth	36
National Autistic Society local branch	35
Other people with autism	25
Local Autism Directory (LAD)	16
Local Parent Partnership Service	14
Autism diagnostic service	7
Online search	4
Other local groups	3
Local Serendipity Group (run by Autism Hampshire)	2
Hampshire County Council Local Offer	2

The highest number of respondents disagreed that there is adequate information available locally about autism/Asperger syndrome services and support (31.5%), followed by those who strongly disagreed (28.1%). None of the respondents agreed with this statement. The majority of respondents agreed or strongly agreed that they would like one place to go to obtain all the information and advice they needed (85.4% in total).

The responses to question 10 – which autism support services would you use if they were available? - are shown in the graph below. The most popular option was a service with local drop-in sessions, followed by an e-mail service. Other services suggested by respondents included autism specialist legal advice service and a befriender service.



Only 29.2% of respondents have the Autism Alert Card or App issued by Autism Hampshire. It is hoped that the other respondents take advantage of this resource as a link to further information about the card was included in the survey.

Respondents were asked what they would want an Autism support service to offer, the answers are listed in table 2 in order of popularity. Employment advice was the most popular, but the other categories received votes across the board.

Table 2

	Response Count
Employment advice	63
Social skills help	62
Autism specific counselling	60
Relationship and friendship advice	59
Crisis help	55
Housing advice	51
Benefits advice	50

Part 2

Using the Autism Support Service run by Autism Hampshire's Community Access Scheme

The survey was targeted at users of the service, but the response from actual users was disappointingly low. Only 13.8% of respondents have used the Autism Support Service (12 out of 89 respondents). There are several ways that they found out about the service, see table 3.

Table 3

Online search	3
School	1
Hampshire Autism Partnership Board	1
Local Implementation Group (LIG)	1
Professionals meeting	1
Autism Hampshire stand	1

The type of support they received are listed in table 4. The most common was employment advice and providing support at meetings/appointments.

Table 4

Employment advice	3
Support at meeting/appointment	3
Autism specific counselling	2
Benefits advice	2
Crisis help	2
Relationship and friendship advice	1
Social skills help	1
Direct payments	1
Info on health and possible AS counsellors	1
Services available locally	1
Housing advice	0

When asked to rate the support that they received, the service was rated excellent by 13.3%, good by 20% and poor by 20%. The comments received were largely negative, one person mentioning that “We were surprised that they didn't offer home visits”, and another that they were “trying to be helpful but mostly just signposting to services (e.g. Jobcentre plus, counselling, social groups) that did not help, were inaccessible or were inappropriate for my needs”.

However, when asked how they would be affected if the service were to cease, there was a range of responses from “awful and suicidal” to “Not at all”. Generally the responses highlighted concerns that if the service was to cease, respondents would be impacted negatively. See appendix 1 for comments. Four of the respondents do not know where to go for help if the service were to cease, others commented that they would seek help from other organisations such as Autism Wessex and HCC SAIL and Local Offer.

When asked how the service could be improved, five respondents commented that a more specialised service including 1:1 face to face visits in the person's own home would be an improvement. Two commented that it needs to be publicised better, especially online, and another two respondents called for better staffing levels within the service.

As we didn't get a very good response from users of the service, we can only make some very general comments about the results. This report will be fed back to the Hampshire Autism Partnership Board and other interested parties at Hampshire County Council.

Appendix 1 Comments on open-ended questions

Question 7 Where do you get information locally about autism/Asperger syndrome services and support? Tick all that apply

Did not know about LAD and SEND

internet

National Autistic Society (at national level)

webautism course university of birmingham

no one really helps us

Local offer; training by workforce development

just searching on line

My son was only diagnosed last year aged 26 after a long fight to get a diagnosis. I haven't needed to get any help as yet as I have been dealing with him myself for 26 years.

HCC training

training from national autistic society

our knowledge of the local area and mainstream and specialist services

I search myself online

AAA service in Epsom

From work

from Assist NAS service that covers NE Hants and has long history of supporting adults in this area

Sometimes informed by Autism Wessex and Southern Health Trust but feeling quite isolated and out of touch

Very difficult to find any

Word of mouth

From my own research via the internet

Network

Question 10 Which autism support services would you use if they were available? Tick all that apply.

Social group

Befriender service

Autism specialist legal advice

I'd use whatever available or appropriate at the time - or nothing if not required.

We find that people need help and support with a variety of issues so need to access generic support that is offered in a person centred way, not necessarily an autism service

A clear point of contact within general adult services other than learning disability team for AS and high-functioning autism

A dedicated team within HCC

there is a one-one service available in Ne Hants. Accessing Surrey services has always been more helpful than those in the South of Hampshire, also accessing groups run by the NAS and SDPP has been really helpful

Question 12 What would you want an Autism Support Service to offer that would help support your needs?

crisis line

Support for the carer and special support for the adult with autism

Home skills advice

Legal advice: autistic people are being unfairly targeted because they require specialist help which the authorities perceive to be expensive (although this is not necessarily the case).

not so much for me but for others I support all are important and others like legal and self harming for example. I suspect all kinds of support for everything neurotypicals require support for are also required by those on the autism spectrum.

Advocacy. e.g with other agencies, GPs etc

Personal care advice

Diagnosis and after support. Courses for people with autism ie anger management, anxiety (or at least be linked in some way to the IAPT services to improve their offer)

communication

Anxiety help

People with autism can get support for most of these issues in other services like SAIL, there is a lack of specialist therapeutic support like the counselling that people tell us they want

continuing education advice, advice and liaison with social care, carers' advice, practical help with eg social life...buddies or similar, advice on integration and involvement in social activities

mentoring/buddying opportunities

Social events, from small board game evenings to discos and speed dating.

Autism help support and advice (not counselling that has problematic models for autistic adults)

Education / training service, employment social enterprise, appropriate social groups

Question 14 How did you find out about the Autism Support Service?

they are nice , yet not enough support for professional help ,,

At stand at an Autism/Aspergers seminar

I haven't!

lig

Professionals meeting

I have been to them. But I feel it's a waste of time as all there do is signpost you to someone else They are the bigger in this area .what good is that?????

Jackie Harvey

Online

They were not able to help

From the Hampshire Autism Partnership Board

No never really been accessible to NE Hants have to travel to Southampton or talk to someone on the phone or try to find a drop in, find Assist in Godalming and Sdpp more helpful. Would not want to lose them

Some helpful advice but little follow up, maybe because I am almost out of area and receive official social care from Autism Wessex. There is little or no support accessible to me in the categories asked about (see question 15). In my opinion DWP/Jobcentreplus has generally been secretive, unhelpful, defensive, uninformed about autism and irrelevant to my needs.

Via the website

website

School

Question 15 What was the nature of the support you received? Tick all that apply.

direct payments , support for mental health appointment ..

Was sent info emails. One-off: accompanied son to an assessment meeting with WCMHT. This led to a Support Worker, but only for a year. Have not received any of the above list.

none

None - not able to meet in Basingstoke, another client was told he didn't meet criteria

No help at all. I don't want tea and sympathy

Support from them in meeting

Nothing as yet

We have referred numerous people with Aspergers to the service for a range of issues

none

info on health and possible AS counsellors

Services available locally

Question 16 If you would like to comment on the support you received, please do so here.

supportive , kind , yet not enough knowledge to deal with complexity

Any of the above list would have been and would be welcome.Had to go to counselling with Olive Branch, Emergency Care Plan with the Princess Royal Trust, and employment advice from A4E but not autism-based.

none

The council commission with funds to help to support people in this area.What is that money being spent on.

APPALLING

We were surprised that they didn't offer home visits and had the view that people with autism 'prefer emails and texts' which isn't always true, people that we have referred have come back to us and said the service wasn't helpful

n/a

Trying to be helpful but mostly just signposting to services (e.g. Jobcentreplus, counselling, social groups) that did not help, were inaccessible or were inappropriate for my needs.

Question 17 If you are currently using, or have used this service, how would you be affected if this service was to cease?

awful and suicidal

We would not be affected if these services were no longer there as we were not aware of most of them! They should be made known about, offered to all, not kept quiet about and not closed down!

I am writing this has someone who has provided support to people with Asperger's to access this service. As we have never managed to actually receive a service we would not be affected at all if the service was to close.

Autism Hampshire's Community Access Team don't help me or anyone i know and i would like funds to go to a service like a day service or groups for adult with autism that offered direct help

No-one else to go to who offers same level of support/advice

Don't know

Not at all, they have not really been any help at all, just sign posted again to somewhere that signposted us back again...

We have found that we if we have the resources to offer a face to face meeting with people with Asperger's, we can support then to access local mainstream and specialist disability services like SAIL and they don't need an autism specific service. They need person centred support from their advocate to establish their needs then they can tell other services this is how they need to be supported. Everyone else has the signposting info that Autism Hampshire has, and if they aren't going to meet with people with Asperger's then I am not sure why the service is needed. I am not sure they were offering a service to people with a learning disability and autism.

I need such a service and I need it to be more effective and relevant to me than it has been.

Would not know where to go to receive be fit or other advice.

It would be a lost point of contact that I direct parent/ carers to.

This has been the only source of information and help I have been able to access it would leave our family. It is so important to have someone to talk to who understands and can advise and support.

Question 18 If you are currently using, or have used this service, where would you go to meet your needs if this service was to cease?

where i go is miles away from where i live

As given in No.16, we went elsewhere anyway for some needs because we were unaware (not told) about the autism services available. Help with relationships, social skills and counselling specific to autism would be hard to find elsewhere. Winchester City Council offers advice on Housing, and JobCentre offers advice on Benefits. Wellness Centre in Winchester offers support but my son will not go near such a place with people with other problems.

In my opinion this service didn't meet our clients needs.

I don't want them to cease as awareness for autism is needed

No-where known to me

Don't know

No where, still haven't found anywhere or anyone to meet our needs, we just get signposted.

The Hampshire Advocacy service is funded to provide advocacy to people with autism HCC SAIL offers local drop ins and a telephone service

Needs are met by other organisations, would not want to lose them also talkplus can be helpful too
Autism Wessex, NAS or my NHS social worker, but I am currently left mostly to fend for myself, leaving me feeling
(being?) isolated, vulnerable and anxious.
Not sure.
Have to rely on the local offer information
Don't know if there is anything else available

Question 19 Please give us your ideas on how the service can be improved

more professional advice more autism therapy led , more support , just more of everything ...
Publicise it to those who need it. People should be referred on diagnosis so they know what's available from the start.
Offer autism-related advice or practical support to groups or 1:1 at a centre, or 1:1 at a person's home, if they cannot
deal with going out. Once they gain more skills and self-confidence they are more likely to be able to go out and meet
others. For bright young people with Aspergers, involve university students with similar special interests, willing to be
a visitor/friend and chat about that subject.

Be able to work with people on a face to face basis over the whole of Hampshire.

We need groups in the Portsmouth community area for adult with autism. Helpful information would be • An
information pack for carers .I have learnt thought looking on the internet and from friend about free community
benefits free ,access cards what care should our autistic people be offered in the way of support by county council. •
Information pack for adult unsupported by family or friends. I think there is a lot of adult with autism unable to seek
out help by themselves in the community.

Don't know

We need support with anxiety and the resultant OCD. We desperately need supported employment/ apprenticeship
but cannot get it.

More promotion on social media as this is an easy way to find information for me.

Face to face visits in their own home or community setting as most people can't travel to the office Not sure people
with autism want a specialist signposting service, they want specialist support either therapeutic or a 'navigator' to
help them access other services

haven't used it, but all things talked about on here are available through others in this area

I have been told that many services I need cannot be made available due to lack of funding and/or appropriate
expertise.

It was already very good.

increased staffing for one to one visits. It's good to talk to people face to face.

More staff / hours available