

## Services for Adults (age 18+) with Autism

A survey of 19 questions was circulated from 30.01.16 – 29.02.16 via Survey Monkey web link relating to housing, services and benefits for adults with autism (18 and over) and their families. A total of 99 responses were received.

### Summary

The majority of responses were received from the Hampshire Local Authority, followed by Southampton. No responses were received from Isle of Wight or Portsmouth. Of the respondents from Hampshire, a high proportion were from the Eastleigh Borough (26.2%), followed by the New Forest District. This is possibly due to more concerted promotion of the survey in those areas

The majority of respondents were parent/carers of an adult with autism (61.7%), followed by 21.3% who are adults who have autism. Just over half of the responses concerned an adult in the 18-25 age bracket (52.1%), while 25.5% of responses concerned an adult in the 26-29 age bracket.

The majority of responses concerned adults who described their condition as Asperger Syndrome or High Functioning Autism (46.2%), followed by Autism with accompanying learning difficulties (38.7%). A very high proportion (92%) actually have a diagnosis of autism/Asperger Syndrome.

Just over half of the adults concerned (56%) received their diagnosis through a Mental Health Professional e.g. CAMHS, and the majority of adults concerned were diagnosed as a child (73.3%).

Many of the respondents had multiple diagnoses before being diagnosed with autism. Of the 33 respondents who had a prior diagnosis, the most common diagnosis was ADHD, followed by Down's syndrome and then Learning Difficulties. There was a variety of other prior diagnoses reported.

A high proportion (60.9%) have accessed further education, but only 20.7% have gone on to access higher education. Only 8.7% have accessed none of the forms of support listed.

The majority of adults concerned live with support (80.7%), there are very few who live independently (19.3%). Of those living with support, most live at home with parents, some have a form of support while living at home, and some are in residential care.

72 out of 99 of the adults concerned receive either DLA or PIP, which is a high proportion. Of the adults concerned who receive other benefits (45.6%), the most common was Employment Support Allowance, followed by Housing Benefit and then Pension Credit.

A third of those surveyed have not heard of Direct Payments indicating a lack of awareness of this benefit. Of those who commented on this question, 4 people have not applied because they have heard that it is too difficult, 3 have no need to apply, 4 were turned down, and 4 did not qualify.

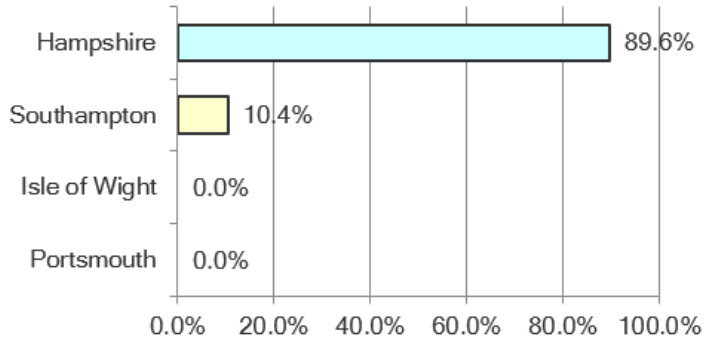
Just over half the adults concerned found the process of setting up Direct Payments straightforward, which is very encouraging. Those that did not commented that the process was insensitive and overly complicated, that there was a fight to get it and it was difficult to communicate with care companies. One respondent had to set up a trust for their dependant.

Exactly half of the respondents who answered replied that Direct Payments meet their requirements well. Of the comments received, it is clear that it is hard to find appropriate support workers to spend Direct Payments on. Many of those who receive DPs find them difficult to apply due to difficulties in finding suitable carers, and find the administration stressful. Only 2 people replied that Direct Payments are excellent.

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

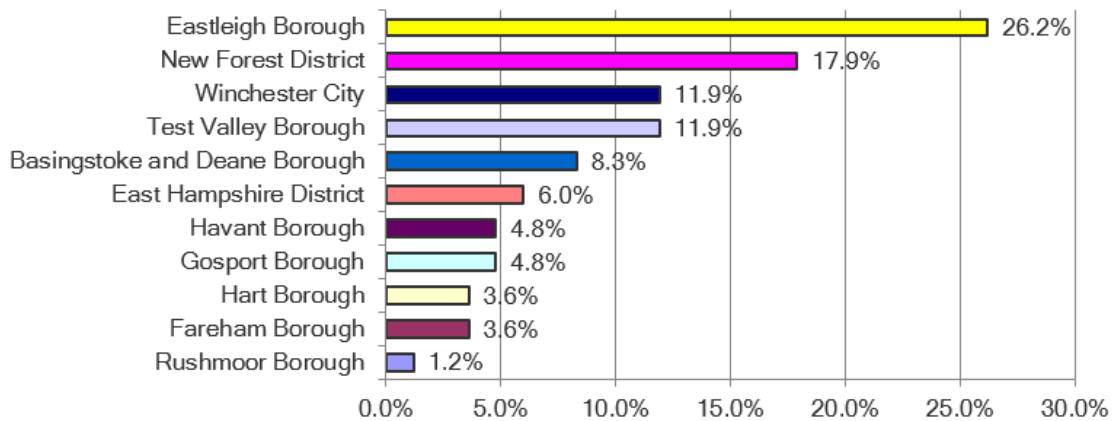
**1. Which area local authority do you live in?**

Answered: 96 Skipped: 3



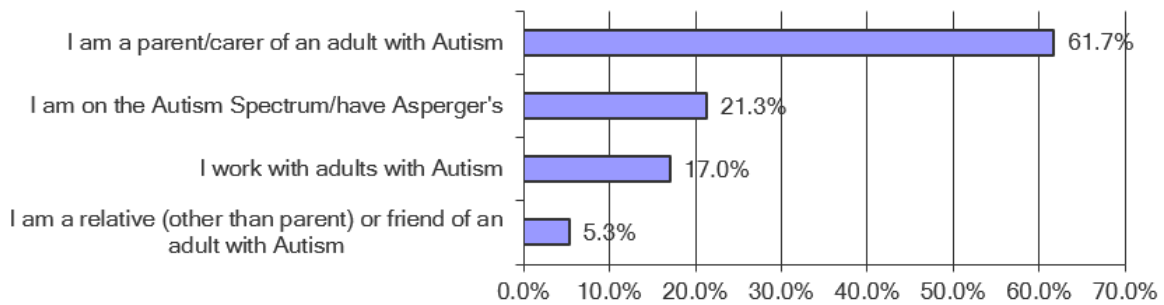
**2. If you have answered Hampshire to question 1, which Districts/Boroughs do you live in? If not Hampshire please go to the next question**

Answered: 84 Skipped: 15



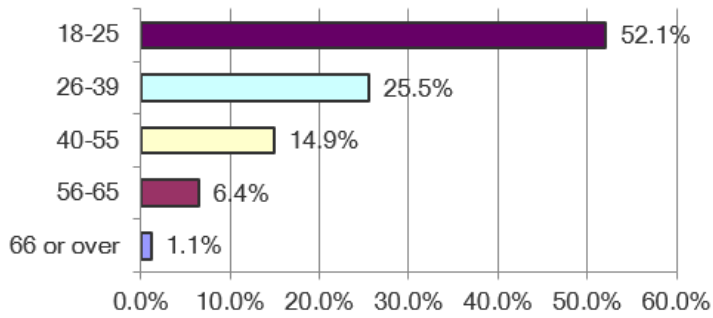
**3. What is your relationship with Autism?**

Answered: 84 Skipped: 1



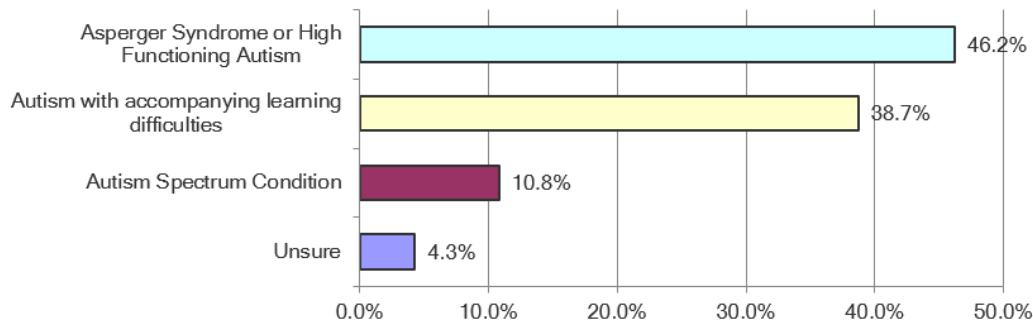
**4. Which age bracket does your person with Autism/Asperger's (or if this is you) fall in to?**

Answered: 94 Skipped: 5



**5. How would you describe the level of Autism? How would describe yourself if this is you?**

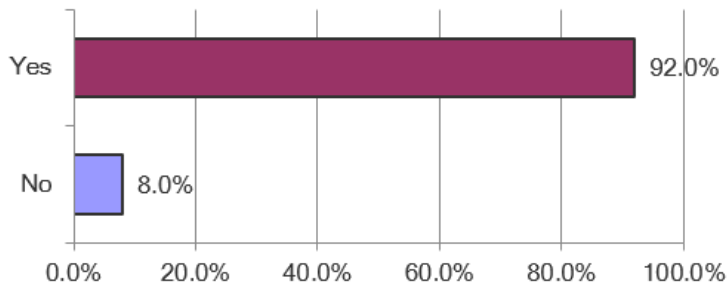
Answered: 93 Skipped: 6



See appendices for all responses.

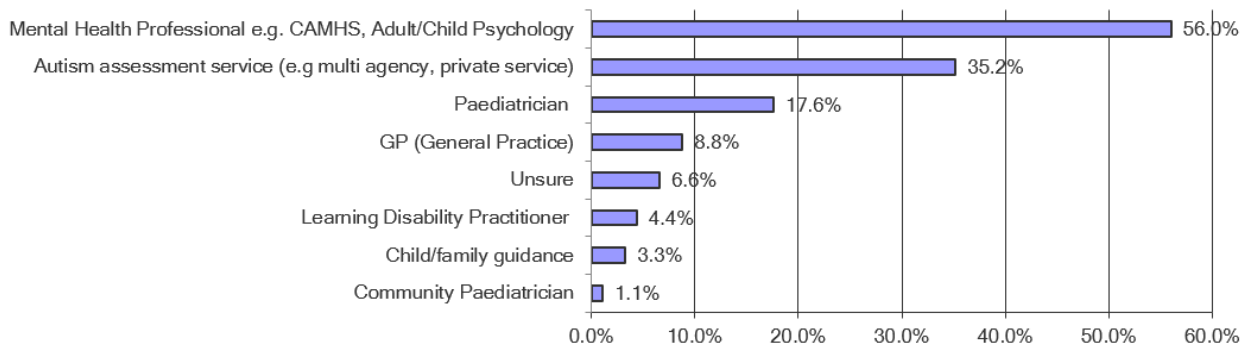
**6. Does the person concerned (or if this is you) have a diagnosis of Autism/Asperger’s Syndrome?**

Answered: 88 Skipped: 11



**7. How did your person (or if this is you) receive their diagnosis? Check all that apply.**

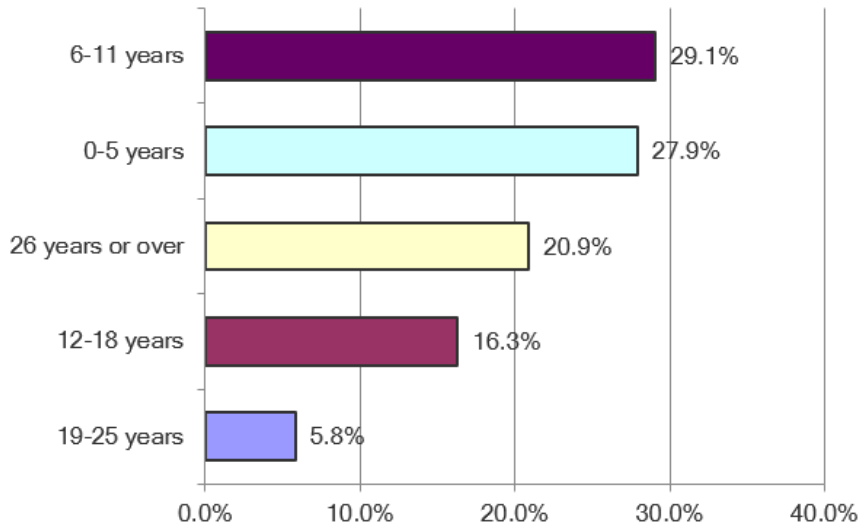
Answered: 91 Skipped: 8



See appendices for all responses.

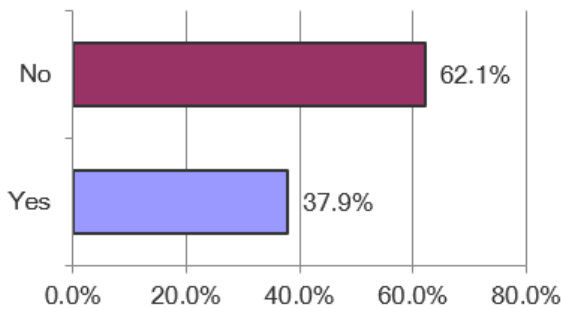
**8. If yes to question 6, at what age did this take place?**

Answered: 86 Skipped: 13



**9. Did your person (or if this is you) receive a prior diagnosis for your condition other than autism? If yes, please comment.**

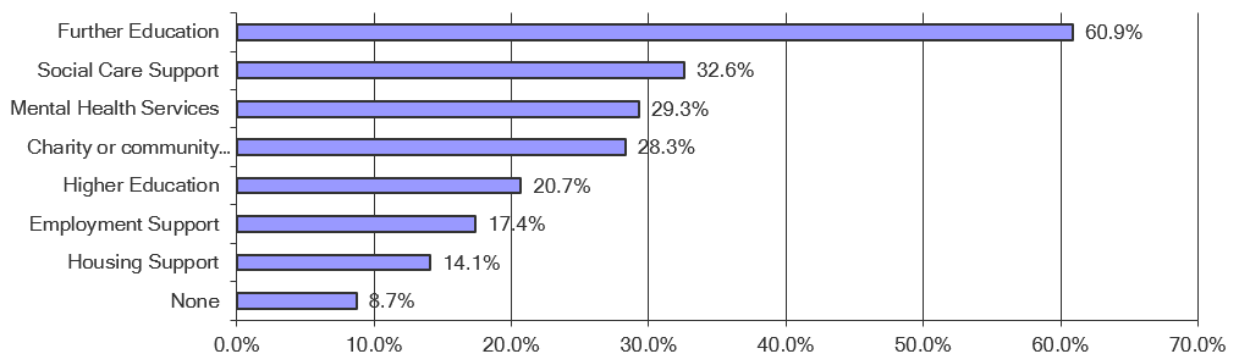
Answered: 87 Skipped: 12



See appendices for all responses.

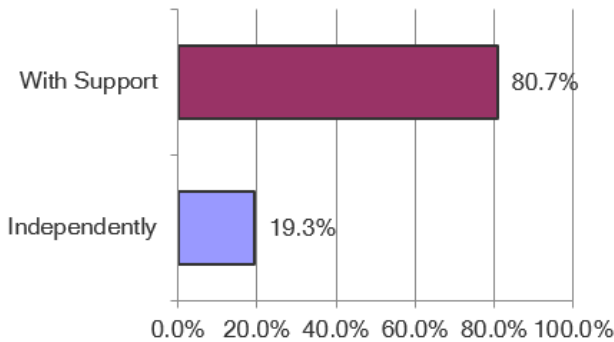
**10. Since the age of 18 has your person (or if this is you) accessed any of the following? Check all that apply.**

Answered: 92 Skipped: 7



**11. Does the person (or if this is you) live independently or with support?**

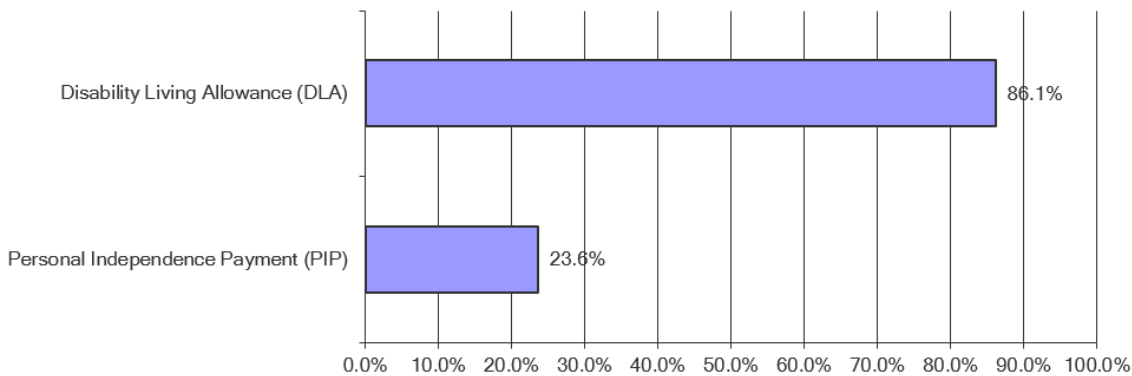
Answered: 83 Skipped: 16



See appendices for all responses.

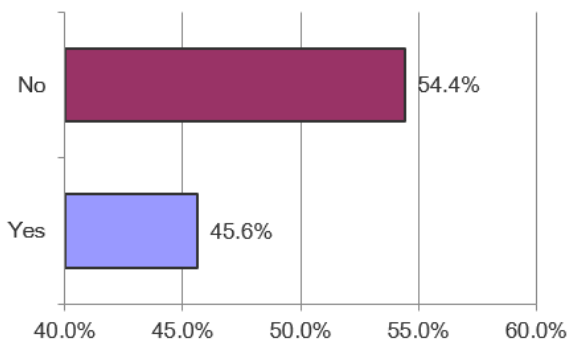
**12. Is the person (or if this is you) in receipt of any of the following benefits? Tick all that apply**

Answered: 72 Skipped: 27



**13. Is the person (or if this is you) on any other benefits? If so, which ones?**

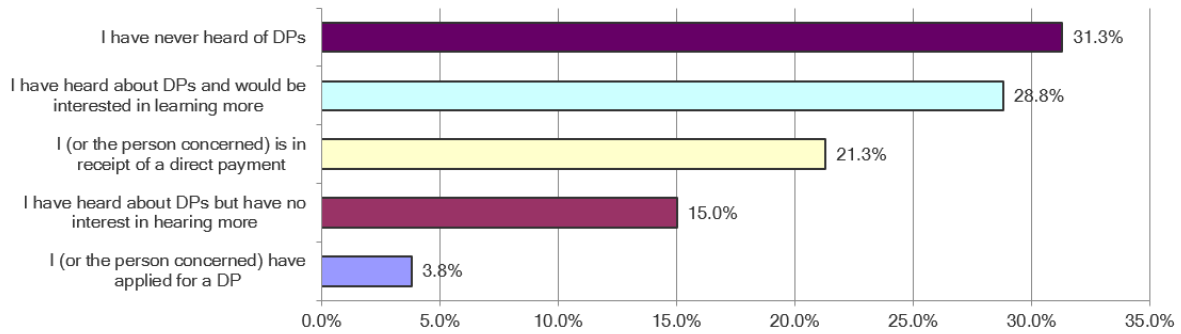
Answered: 79 Skipped: 20



See appendices for all responses.

**14. Are you or the person this survey concerns in receipt of or have you heard about Direct Payments (DP) from the Council to purchase services?**

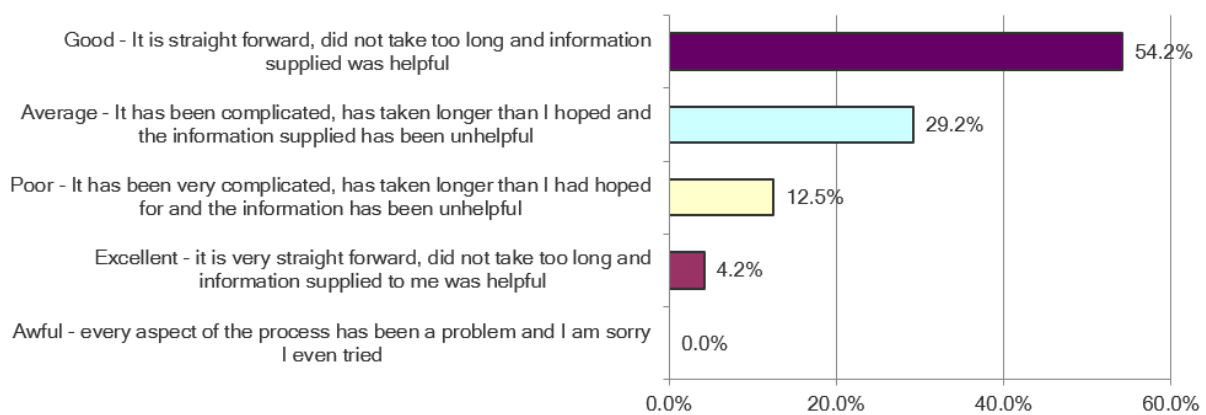
Answered: 80 Skipped: 19



See appendices for all responses.

**15. If you (or the person this survey concerns) are in receipt or have applied for Direct Payment which answer below best describes the process of having one set up from your experience?**

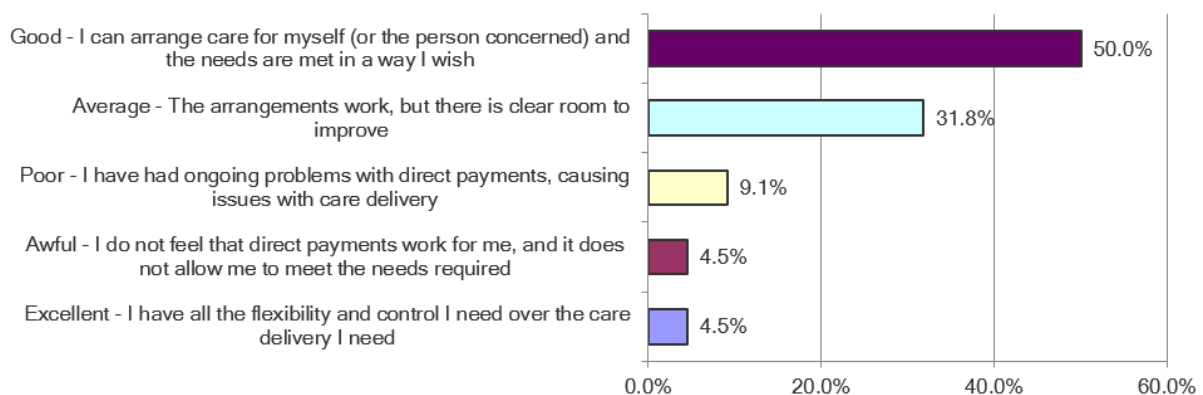
Answered: 24 Skipped: 75



See appendices for all responses.

**16. If you (or the person this survey concerns) are in receipt of a Direct Payment, which answer below best describes how well it meets your requirements?**

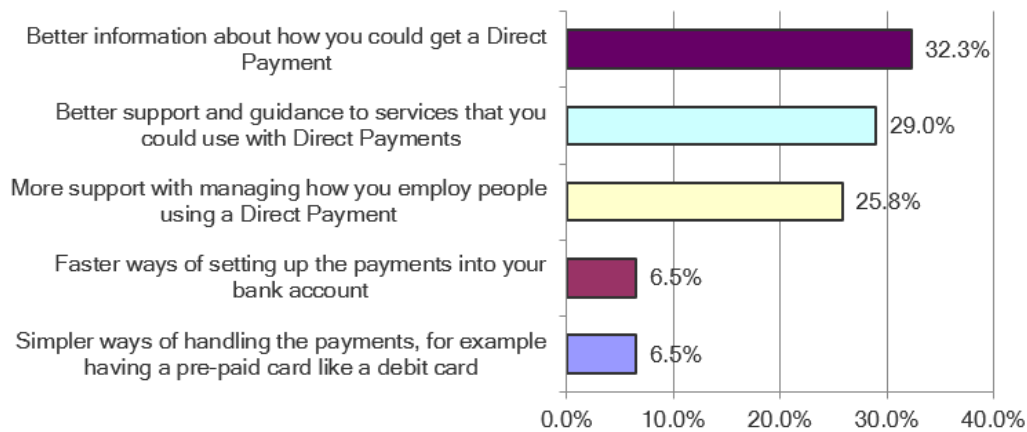
Answered: 22 Skipped: 77



See appendices for all responses.

**17. If you could change one thing about the current Direct Payments offer that would make it more attractive to service users, what would it be?**

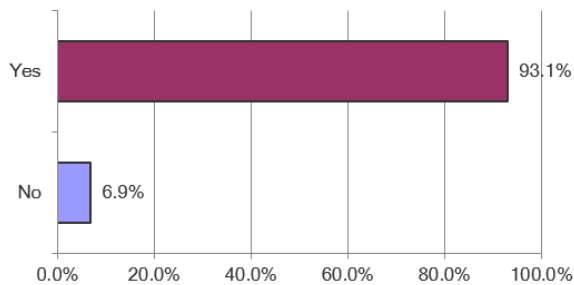
Answered: 31 Skipped: 68



See appendices for all responses.

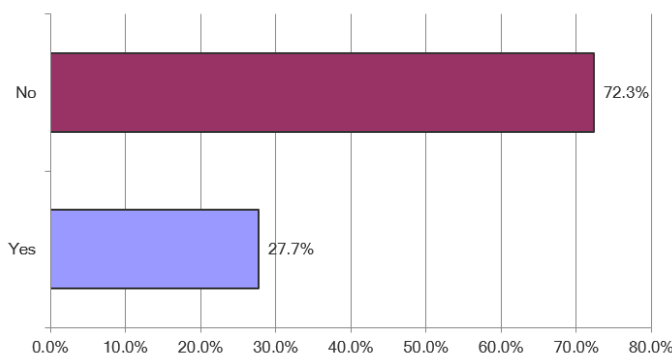
**18. Are you happy to receive further surveys from Hampshire Autism Voice?**

Answered: 87 Skipped: 12



**19. Are you a member of the HAV network?**

Answered: 83 Skipped: 16



**Appendices – full responses to open-ended questions**

**Question 5 – How would you describe the level of Autism? How would describe yourself if this is you?**

Asperger Syndrome with learning disabilities
complex diagnosis
Down's syndrome with autism.

level 2 soc. communication etc level 3 changes rigid thoughts behaviours etc
Pathological demand avoidance syndrome
Regressive autism
We work with children and adults with autism and learning disabilities as well as those with Asperger's or high functioning autism

**Question 9 – Did your person (or if this is you) receive a prior diagnosis for your condition other than autism? If yes, please comment.**

ADD
ADHD
anxiety, bad behaviour
borderline personality disorder, mental health, laziness, etc
Delayed speech
Depression
Depression/anxiety
Downs Syndrome
Down's syndrome with multiple sensory disorder
Downs syndrome. All of my sons odd behaviour was attributed to this and I fought very hard to get someone to listen and eventually got a diagnosis of autism at 25!
Dyslexia and Dyspraxia
dyspraxia
global developmental delay
Global developmental delay, sensory processing disorder and DAMP (Deficits in attention, motor and perception)
He was told he was over anxious child for nearly ten years.
Hyperactive
Language delay and then Language Disorder
LD
learning disability
Learning disability and OCD
Left Hyperplastic Heart Syndrome
Many adults we work with have received a mental health diagnosis and then receive a diagnosis of autism later in life
My daughter has had a lot of diagnoses of autism, but the Clinical Commissioning Group have constantly tried to conceal these in order to avoid having to provide the necessary services.
Oxygen deprived birth
PDD
social communication disorder and a language disorder
Speech and language delay
Unspecified personality disorder (noting confidence/anxiety and self-esteem problems, tendency to fixate on special interests and methods, implied attention deficit problems and dyslexic symptoms

**Question 11 – Does the person (or if this is you) live independently or with support?**

Although we have started to consider moving our daughter on, our concerns at the level of support that she would receive have stopped us doing this. The whole purpose of the doctors referral and very thorough assessment process undertaken by SW and NEH was to prove that she is autistic and therefore needs considerably more support. She could never live alone or independently.
At home
At home with 24 hour support by parents
At home with family
At home with his mother and siblings
At home with parents
at residential college...no other support when at home with me holidays and alternate w/ends



Currently at term time specialist residential college
In residential care
but with night person and morning carer
Dependent to some extent on support from autism support charity (through Hants Council) and from family (mother)
Family
HCC "Shared Lives" scheme
He lives with his parents due to his OCD
He needs a lot of support and we find it extremely hard to cope. We have asked for help, but await SW allocation
I live at home with my parents
Lives at home with parents
Lives with me his mother
Lives with parents
My daughter used to live independently with support when she had Direct Payments, when she was very happy and integrated in to the community. When Direct Payments were withdrawn, and she was passed over to "Continuing Care", the quality of care (by private agencies, not specialists in autism) became very poor, and she was then taken off to an ATU and then to a non-autism specific care placement, where she is very unhappy, self-harming and depressed and in great danger.
My parents help me a lot, but no formal support.
My son is living with us at home
My son lives at home.
Residential home
Still at home, rarely goes out, never alone
Still lives at home with parents
Still looking for supported living accommodation without success
Supported Living
We work with people who live independently, and those who have support as well
with family

**Question 13 – Is the person (or if this is you) on any other benefits? If so, which ones?**

Carer's Allowance
DLA then PIP
don't know
DWP EESA
EESA
Employment and support allowance
Employment Support Allowance (ESA), Council Tax Benefit
Employment Support Allowance, Job Seekers Allowance
Esa
ESA
ESA
ESA
ESA
ESA
ESA
esa
Esa
ESA
Esa
Esa mobility allowance
Esa, housing and council tax benefit

Housing benefit & ESA
Housing Benefit & ESA
housing benefit, incomesupport
Housing benefit,child tax, working tax and child benefit
Income Support
jobseekers
Just applied for Employment Support Allowance
Not sure - don't deal with his finances
Pension credit
pension credit
Refuses to claim job seekers allowance as he wont go to the job centre again
Rent and council tax and pension credit
SDA, IS,
Tax credits
Unemployment, housing
Unsure
Working tax credits, disability premium

**Question 14 – Are you or the person this survey concerns in receipt of or have you heard about Direct Payments (DP) from the Council to purchase services?**

At present my son has no need to purchase additional support or services
But have heard that having to employ support is difficult to manage
Considering this option as the support provider for the last 13 years has not rebid for the contract due to change to 'cluster' payments
do not think would qualify
Had a dp until CHC funded- not allowed to apply for personal budget
He works and does not need benefits
I am put off by the apparent need to keep detailed administration records to justify DP claims
I am utterly exhausted with the 24/7 care to take on yet another form/hassle with too many unknowns - as successive govts keep moving the goalposts and hitting the vulnerable!
I do not consider that my son would be eligible since he is high functioning
I don't deal with his finances. In any case, in our area people report that they get many wrong bills for services, and there's a lot of hassle; it's not encouraging.
I have been told that my son's case cannot be open to social services and mental health at the same time therefore Hampshire social services closed case.
I was turned down
Is this in addition to DLA?
Lo al authority is not interested in providing Direct Payments. This has happened in the case of a lot of other people besides my daughter. The local health authority are not interested in providing the equivalent Personal Health Budgets.
Lokking after a person with ASD is stressful enough without the added pressure of having to source carers, train them, retain them, becoming an employer, accountant ...
my son had dp as a child but now he is 18yrs old it has stopped
Not met critra
not sure
Received in the past, although not now eligible
Some people have heard of direct payments, but they can only be accessed if you are eligible for ASD support, which many peoplw who have Asperger's are not
SUs are offered this option
They are relevant for them
Used to be in receipt of DP before my sons 52 week residential placement.
We have DP to pay someone to take our son to social groups

**Question 15 - If you (or the person this survey concerns) are in receipt or have applied for Direct Payment which answer below best describes the process of having one set up from your experience?**

Don't know (but I have heard some horror stories about Direct Payment administration)

Had to fight and get a carers assessment to get it

I found the record keeping complicated and time consuming

it is very hard getting care companys to talk to you re problems or even answer you

It took so long for them to send me a letter telling me what it was awarded for and how much for each thing.

the hoops the person had to jump through were insensitive and did not take into account their level of anxiety

This answer is re Nhs

When my daughter was in receipt of Direct Payments, it was very hard work, we had to set up a Trust to receive /administrate the payments,; my daughter was happier at this time than ever before.

**Question 16 - If you (or the person this survey concerns) are in receipt of a Direct Payment, which answer below best describes how well it meets your requirements?**

At present receive nominal amount monthly for respite care

Direct payment was excellent

Don't know (but I suspect it would burden me with more bureacracy and anxiety)

For a working parent, we need ease of access to sipport services for our young people. Not more responsibility and stress, followed by guilt when things don't work out. it has taken 18 months since receiving payments, to finally get to use them. I wish the money I paid back had gone into one of the youth facilities wr access, instead.

Have one very good support worker but are having problems finding others to cover the hours we have been awarded.

it is just for four hours support to go out. Parent manages this

More help finding and recruiting the right person to give support.

There is nowhere to recruit appropriate PA's

Unsure but since working with people with Autism I have not heard good feedback.

We pay for day services, taxi to day service and someone to take him to social groups.

When my daughter had Direct Payments, it covered her needs very well.

**Question 17 - If you could change one thing about the current Direct Payments offer that would make it more attractive to service users, what would it be?**

all of above

All of the above, plus accessible advice/help to reduce anxiety regarding receipt/invoice/account record keeping

I have asked for help from social services (not sure if this is how you get direct payments) after several requests and months waiting my son had a needs assessment, and meets criteria for support but has had no care plan and no support and they have not done requested carers assessment

Information about where you find people to employ.

More opportunities to use appropriate services without having to deal with the administration.

My concerns are with Nhs which is who you should be surveying

No comment

Recruitment of suitable individuals to help our son was a challenge. It is not easy to recruit and retain appropriate carers. The recruitment process re CRB/DBS clearance takes time, as does setting up as an employer with HMRC, if recruited carer is not self employed

When we had Direct Payments, we were not given any guidance about how to use them.