

“MIND THE GAP”

A Study of Health and Social Care Access Issues for Adults with Asperger’s Syndrome and High Ability Autism in Shropshire



30 September 2014

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Special thanks to members of the Autonomy group in Shropshire
who contributed to this survey as respondents.

This survey is dedicated to our dearly loved and much missed past members of
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FOREWORD

Autonomy is the largest independent self help and social group of its kind in the area. We fill a gap in service provision for over 90 active members all of whom have autism/Asperger's syndrome and offer regular, consistent and predictable autism specific events and activities; we are often referred to by our members as a "social lifeline." Autonomy supports those with or without a diagnosis of autism/Asperger's syndrome and many of our members are those who have been recognised and subsequently supported through the diagnostic process in adulthood; we recognise that when an adult becomes aware of his/her autism this can be a traumatic experience. He/she is very vulnerable, often confused and full of questions which need answering. This is where the support of an autism specialist mentor as well as peer support from an autism specific self-help and social group is essential. Currently all of these services are provided by Autonomy without any statutory funding.

Having run the Autonomy group for the past ten years, I am aware but, purely anecdotally, that many of our members do not have had full access to local provision of health and social care. The sad - and possibly preventable - early deaths of our late members, Dr Danny Beath and Michael Harvey reminded us of this issue and led us to explore whether other members might also be at risk of health issues and if this may be linked to their autism/Asperger's syndrome. We were also aware that some of our members were supported by Social Services but others, with the same or even more complex conditions, were not. We therefore wished to also investigate access to social care.

Phil Wylie and I had already completed a survey in 2013 on Very Late Diagnosis of Asperger's Syndrome (VLDAS) which highlighted many issues. Numerous questions still remained unanswered particularly with regard to our younger members. A further in depth survey would definitely complement and build on our research base, with the added bonus of providing employment for some of our members. We were fortunate that Healthwatch Shropshire offered grant funding - for hard to reach individuals - and were successful with our application.

We therefore ran our study with several aims. One was to learn about our members' experiences of healthcare; another was to see if any changes or improvements could be made to enable them to be more accessible to our members. A further aim was to explore our members' statutory rights under the Autism Act 2009 and the Autism Strategy 2010, and to see how far this had been implemented in Shropshire. We also wished to investigate if our members were aware of this potential support or and if they knew how to access it. Thanks to Healthwatch Shropshire funding this valuable project, we were able to interview 30 local people with Asperger's syndrome and we hope that our results will not only make a difference but inspire change in service provision in Shropshire.

Sara Heath

SUMMARY

This Healthwatch Shropshire funded survey was specifically designed to access “Hard to Reach” communities and our group is comprised of people who, due to their disabilities, find it difficult to engage in mainstream activities. People with Asperger’s syndrome and high ability autism are diagnosed with several main areas of difficulty including social communication, flexibility, different cognitive processing, understanding others and being able to predict what they will do, the ability to interpret their own emotions and those of others, to read body language and facial expression, and many and varied sensory issues. Most have a special interest and focus that can take up much of their time and can affect their motivation and energy levels. People with Asperger’s syndrome and high ability autism can therefore be very difficult to connect with and, though often vulnerable for the above reasons, are often not known to any statutory services, including health services. They are often Ignored and Ineligible (<http://www.autism.org.uk/about-autism/our-publications/reports/our-policy-and-research-reports/ignored-or-ineligible.aspx>).

Asperger’s syndrome and high ability autism are both developmental disabilities, but affect individuals who have IQs above the threshold for eligibility to the Learning Disability Service, and those who do not currently meet the criteria for the Mental Health teams. Many are therefore referred to Autonomy as there is little other provision. As we fill much of this gap in services, it is therefore likely that many of our Autonomy members will also have health inequalities due to not being considered to be an “eligible,” “at risk” or “vulnerable” group - when we believe that the opposite is most probably the case. The 2008 National Autistic Society I Exist Campaign (<http://www.autism.org.uk/get-involved/campaign-for-change/learn-more/our-campaigns/past-campaigns/i-exist.aspx>) highlighted the national lack of support available for people with autism spectrum conditions and this research contributed to the passing of the Autism Act 2009. The NAS is also working hard to ensure that the new Care Act to be passed in 2015 fully takes into account the needs of our client group.

Plans are presently being made to improve service provision in line with the revised local Shropshire Autism Strategy and the Think Autism 2014 agenda, but there was little service provision when we started our survey in May this year, and the situation sadly remains the same at time of publishing. In the meantime the voluntary sector comprising Autonomy, Autonomy Plus, the NAS social group and the Shropshire NAS Support Group provide most of the Asperger’s specialist support for these individuals, and Shropshire and Telford Carers’ Support (STACS) provides much valued carer support.

As our survey was funded by Healthwatch Shropshire, we assessed access to health and social care services for our Shropshire members. We therefore investigated how the health services in general supported our local people with

Asperger's syndrome and whether they understand the condition and the needs of our members/respondents.

During our survey we were given many examples of misunderstanding and ignorance about autism/Asperger's syndrome - which could well be due to deficiencies in training - among GPs, general hospital staff, staff at psychiatric hospitals, psychiatrists, mental health professionals and dentists. Because autism is such a complex and diverse disorder, and "a spectrum" or, more appropriately a "continuum", people with autism very much benefit from specialists who have a sound training in the diversity of this neurological condition. Our survey highlights incidences where our members consulted doctors or other health professionals who did not acknowledge, make adjustments for or even understand autism/Asperger's syndrome, the results of which were wasted time and resources, confusion and frustration for the patients, and for some, possible further harm to their health.

Most people with Asperger's syndrome and high ability autism struggle with communication and social interaction; this is a diagnostic criterion and due to their condition. Many experience life in the mainstream world as confusing, anxiety provoking and mentally over loading, finding it easier and less stressful to be alone most of the time, with few friends and very limited social lives. This social isolation/or anxiety can at times be therapeutic but can also lead to the development of mental and physical health issues before or after identification with the condition, especially in late adulthood if they are without supportive families/carers or partners. For the above reasons we would have expected that many of these individuals were known to and under the care of the Mental Health team or Social Services, or aware of their rights to request or be assessed for this support - but we discovered that the majority of our members do not have, and have never had, **any** support from these statutory services. This evidence of unmet need is why we have named this survey "Mind the Gap."

Another area of interest in our survey is the diagnosis of autism/Asperger's syndrome in Shropshire. After being told of the condition, the first port of call for many adults seeking a diagnosis of autism/Asperger's syndrome will usually be the GP, and the diagnosis in Shropshire is usually medically confirmed after a referral to a psychiatrist. We noted that many of our respondents spent a very long time waiting for a medical diagnosis, and many had been diagnosed and treated for a previous mental health or behavioural condition before their autism/Asperger's syndrome had been recognised.

A further area of interest was access to dentists where we noted that many of our respondents had difficulties remaining on the dentist's patient list and so had not visited a dentist for a considerable period of time, which could lead to quite obvious health related issues.

Due to recent NHS drive to improve the poor physical health of people with a

learning disability in the UK : <http://www.improvinghealthandlives.org.uk/publications/topics/Learning%20Disabilities> - Shropshire Council and the CCG now offer annual physical health checks to individuals with autism who meet the Fair Access to Care eligibility criteria for the Learning Disability Team and are known to or supported by Social Services; it is acknowledged that these individuals are often unable to communicate when they are in pain or feeling unwell and the checks are administered through the GP practice. These checks are also available to those who are on the Severe Mental Health Register (namely for Bi-Polar, Schizophrenia, Schizoaffective Disorder and Psychosis) and patients are sent a reminder to attend the appointments:
<http://www.rethink.org/living-with-mental-illness/wellbeing-physical-health/health-checks>.

We at Autonomy are aware that autism/Asperger's syndrome can affect a person's sensory appreciation; we therefore asked our respondents about their awareness of pain and feeling ill and how they cope when unwell. Our results showed that many of our respondents have a high pain threshold, were not aware of pain, or slow to respond to it, and also did not ask for help when they were unwell. We asked if our respondents self-neglected or self-harmed and a large number of them did so. Some readers may be disturbed by this section as our respondents told us they self-harmed to cope or to express emotion and did so by cutting themselves with scalpels, pencil sharpener blades and broken razors which often caused severe nerve damage and needed stitches or surgery; bit themselves; bit their nails to the quick, and also their cuticles, scratched themselves with their nails or razors until they were raw; picked/pulled at loose skin and/or scabs until bleeding (often without being aware that they are doing so); pulled at their hair or their hair out (again, often not being aware of doing so); burned themselves with lighters or aerosol cans; thumped themselves with their fists on body parts, banged, bumped or thumped their heads, sometimes with their fists and sometimes on the floor; or rhythmically pulled or snapped fingers and twisted or pulled their necks. Others told us they overdosed with prescription or non-prescription medication or self-medicated by drinking strong alcohol, taking more prescription medication and non-prescription medication than they should, e.g. pain killers; or by taking illicit drugs. Some therefore are or have been frequent attendees at Accident and Emergency Departments. It was therefore a concern that so few of our respondents were considered eligible for an annual health check despite having similar issues or even more extreme difficulties to those who do, and often living without the support of carers or family members.

Some of our respondents choose to, or have to live alone, due to the sensory, flexibility, theory of mind, and social and communication problems of having an ASD; a large number live on low income or are not able to manage money. Our 2013 VLDAS survey found that only 15% of our respondents worked so our new respondents would therefore probably rely on out of work benefits or tax credits. Some of our respondents are either very under-weight but we found that nearly

two thirds are overweight or obese so may have health issues as a result of not eating a balanced diet – even if they know what one is, possibly also due to the sensory and flexibility problems linked with having autism. Our respondents may well be socially isolated even if they attend our groups, as these occur around twice a month; some suffer from anxiety and depression which we have found to be commonly experienced by those on the autism spectrum, and many do not cope well with talking therapies, as this means speaking to more strangers.

We felt that our respondents would very much benefit from a yearly health check as they struggle with the same issues as those with a learning disability and many who are supported by the mental health teams. We asked if our non LD/MH supported respondents would attend a yearly health check. 21/25 agreed, especially if they were supported to attend. This also raises the issue of the provision of funded and accessible advocacy support for our respondents, as this is not easily available for our client group, as this is usually again provided to those with acknowledged “eligible” needs.

We feel that the provision of an annual health check and funded autism specialist advocacy support for people with high ability and Asperger’s syndrome to attend it would be a cost effective way to support our respondents to better health.

SURVEY OBJECTIVES

The main objective of this survey is to identify problems with access to healthcare provision for residents of Shropshire who have Asperger’s syndrome or high ability autism. Most aspects of the healthcare system are considered, including general healthcare, the service provided by GPs, dentistry, mental health services, psychiatrists, eye care, accident/ emergency/crisis and out of hours services, general and psychiatric hospitals and autism diagnostic services.

A further objective is to explore problems with access to social care provision for our respondents and whether or not they were offered their statutory rights.

Where gaps and unmet needs are identified in healthcare provision we have stated our respondents’ comments and suggestions for improving services. The comments included are written in their own words which have not been edited. Some readers will find some descriptions, especially that of self-harm or suicide, disturbing, upsetting or challenge to read, but they are the patient views; and we, as their advocates, will tell their stories.

NB. We would also like to note that although our survey is based on Shropshire people with Asperger’s syndrome and autism, it is likely that the issues raised in the report will be similar to those of individuals in other counties throughout the UK, and will reflect national, not just local, access problems and gaps in provision.

METHODOLOGY

Sampling

All 30 survey respondents were members of Autonomy, (Shropshire), during the period of data collection (between 2 May 2014 and 12 August 2014). Moreover, all of the participants lived in the county of Shropshire during the aforementioned dates and had a diagnosis of autism/Asperger's syndrome except two individuals who identified with the condition but did not have a medical diagnosis.

Most of our respondents live within 10 miles of Shrewsbury. Our harder to reach groups are in North and South Shropshire, including Oswestry, Whitchurch, Market Drayton, Shifnal, Ludlow and Bridgnorth.

Autism affects at least 1% of the children in the UK population:

http://autistica.org.uk/document_downloads/Reports/Autistica-1-100-Report.PDF

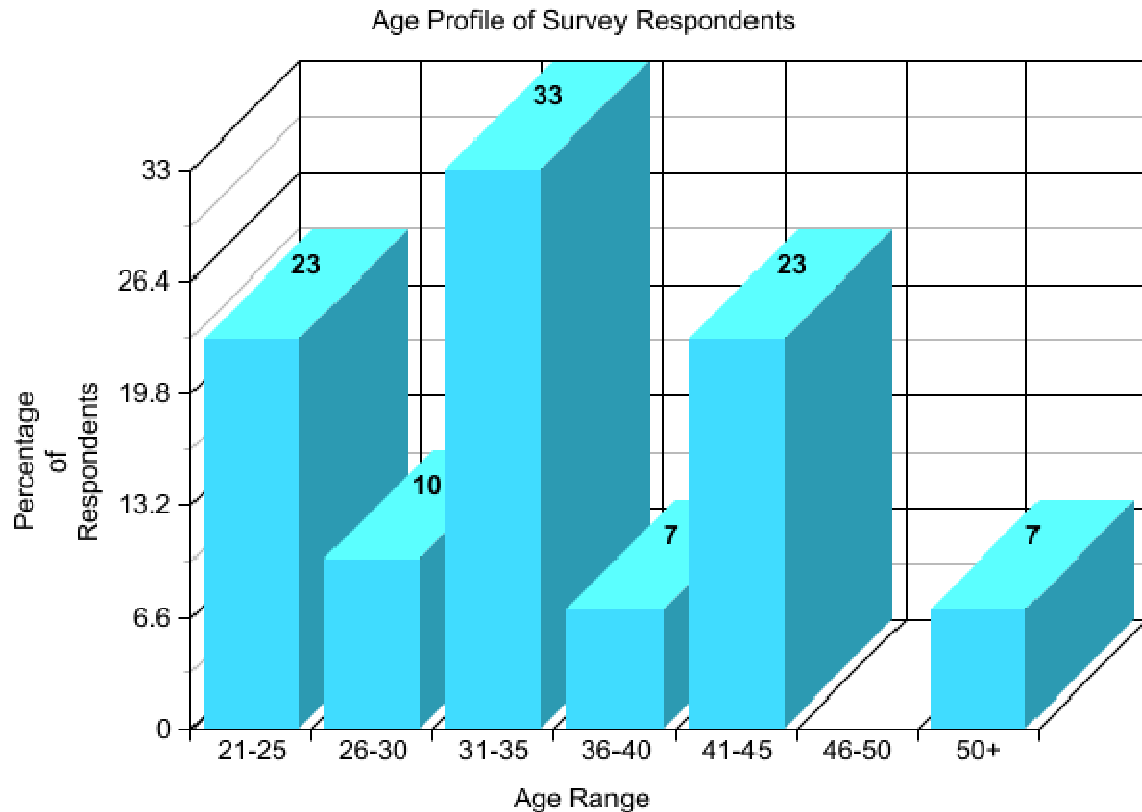
Autism is a life long developmental condition and children with autism grow up into adults with the condition – using these statistics autism could therefore affect about 1% of Shropshire adults with 0.8% of them being male and 0.2% being female, although there are many who feel that women are under-represented in these statistics and other studies have questioned the 1:100 ratio as being too low. For this reason there could actually be many more with the condition living in the UK than previously thought. Results from the 2011 Population Census show that there were 306,100 adults and children living in Shropshire, equating to 3061 people with ASCs (autism spectrum conditions) living in the county, of which around 612 (20%) will be children. We expect to have approximately 2500 adults with ASCs living in Shropshire, around 80% of whom will have high ability autism spectrum conditions and as far as we are aware, the majority of whom will not be known to statutory services or organisations.

Autonomy is linked with of over 200 people with autism/high ability autism/Asperger's syndrome who live in the geographical county of Shropshire and we have over 90 active members who attend social events on a regular basis.

The youngest survey respondent was in the age range 21 – 25 and the oldest was over 50 years old. The median age range in this survey was 31 – 35 years of age.

Throughout this survey our 30 respondents may refer to themselves as having autism but will have a diagnosis of Asperger's syndrome (AS) or high ability autism, autism spectrum disorder, autism spectrum condition, or autism and some will use these terms interchangeably.

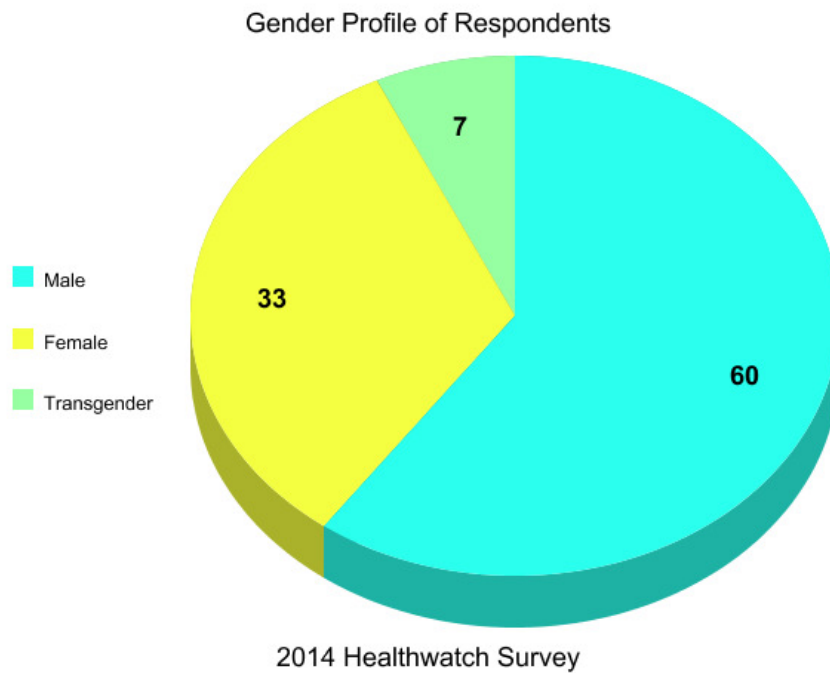
Figure 1: Age profile of survey respondents



2014 Healthwatch Survey

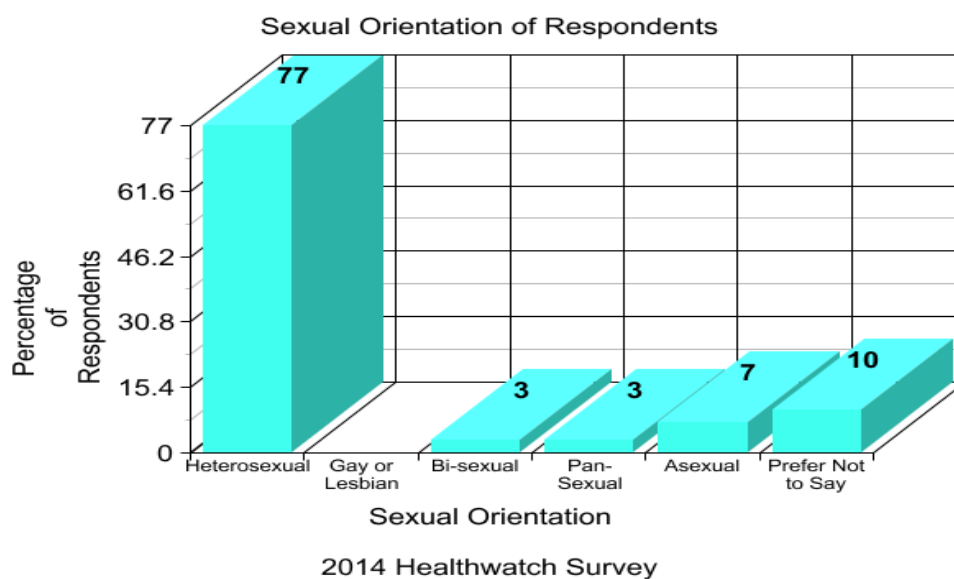
As illustrated in Figure 2 below, one third of our 30 survey respondents were women, 60% were men, while the remaining 7% identified themselves as being transgender. A possible reason for the relatively large population of men in this survey compared with women is that it is thought be easier to identify and diagnose autism in men as the original diagnostic criteria were based on dominant male characteristics that Hans Asperger - after whom the syndrome was named - noted in young boys and because it is believed that women tend to have more cognitive empathy and better superficial social skills than men. With 33% of our survey respondents being female, this survey has more than the national average of females with the condition. This is not surprising as Autonomy provides a dedicated social group specifically for women and those from the GBLT (Gay, Bi-sexual, Lesbian and Transgender) community who identify as women, run training in the Awareness of Women with the condition and work closely with Autonomy Plus who are specialists in the recognition of autism and Asperger's syndrome in women.

Figure 2: Gender profile of respondents



Just over three quarters (77%) of our population of respondents said they were heterosexual. The remainder of the respondents comprise 3% who identified as bisexual, 3% who are pan-sexual, 7% who are asexual, one of whom was “pan romantic” and the other 10% who did not answer.

Figure 3: Sexual orientation of respondents



Data Collection

Sara Heath widely publicised the survey and asked Autonomy respondents to volunteer. She made the announcement at Autonomy social events and in the Autonomy bi-monthly newsletter which was sent to over 200 individuals in the area.

Data was recorded during one-to-one interviews in private, usually in the person's own home. The interviewers, Sara Heath and Eric Heath asked the questions face-to-face and recorded the information on pre-designed questionnaires after a small pilot. The completed questionnaires do not show the identity of the respondent, only an identification number.

We have already undertaken a previous self-funded research project into Very Late Diagnosis of Asperger's Syndrome. In this Healthwatch Shropshire supported survey we used several quantitative research methods including the development of a questionnaire with appropriate open and closed questions that are not leading, identifying a sample of respondents, gaining permission to use the data. We also explored several areas of need in our case studies (Appendix).

Having run a social group for over ten years we are very aware of the difficulties of communicating with our respondents and were prepared for this. We had a range of ways to contact people by mail (with a stamped addressed envelope), email, direct messaging via social media and Skype to encourage its completion. Experience and expertise in this area was gained from our previous survey which was well designed and quite clear and easy to complete; but we were able to have face-face interviews with all 30 of the volunteers, due to being well known to them and trusted by them. Our data was sorted, transcribed, collated, analyzed and presented thematically into a clear report complete with graphs by one of our members.

Ethics

The only members of Autonomy who have access to the real identities of survey respondents are the interviewers, Sara and Eric Heath. The interviewers allocated ID numbers to each of the respondents to protect their identities which ensures that no one else would have access to their completed questionnaires or find out about their neurological conditions.

Each respondent was briefed about their rights before they were accepted as survey respondents. Sara and Eric Heath explained to respondents that their personal identities would be kept confidential and they were aware they can access and read their personal data – the questionnaire - on request as stated in the Data Protection Act. Each respondent has a right to the protection of anonymity before, during and after the survey so real names of respondents are not published in this survey report.

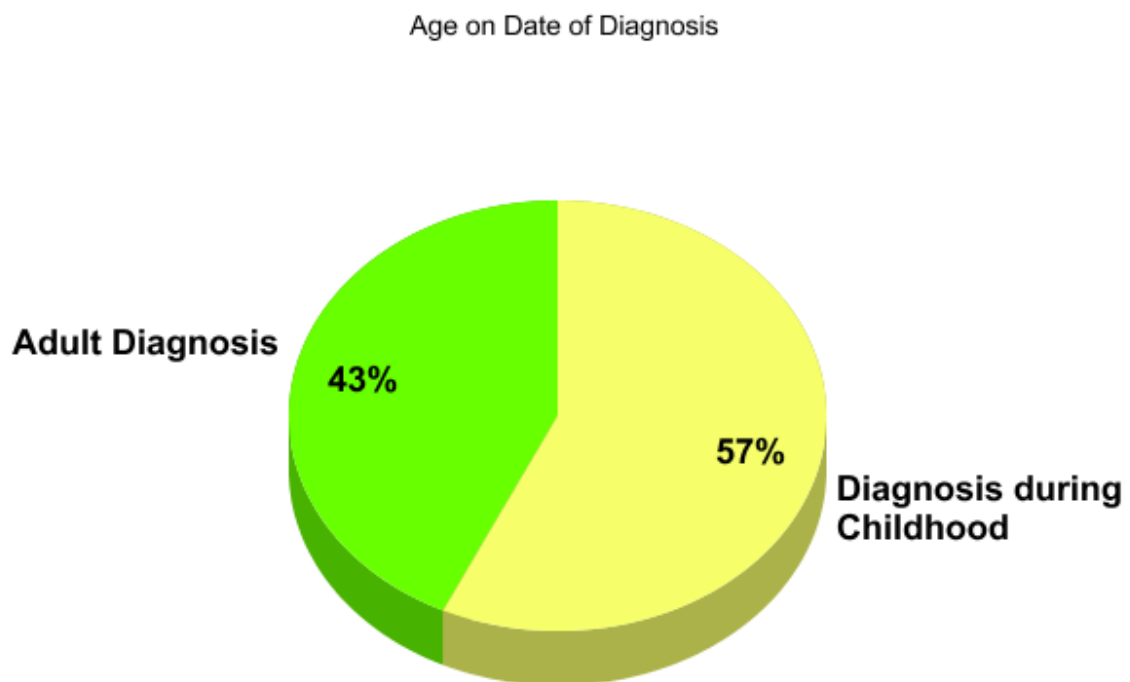
RESULTS

SECTION 1: DIAGNOSTIC PATHWAY

1.1 Age on date of diagnosis

Although respondents were not asked how old they were when they received a diagnosis, we know whether our respondents were diagnosed as children or during adulthood. The majority of respondents (57%) were diagnosed during childhood while the remaining 43% were diagnosed when they were adults.

Figure 4: Age on date of diagnosis



2014 Healthwatch Survey

1.2 Impact of late diagnosis

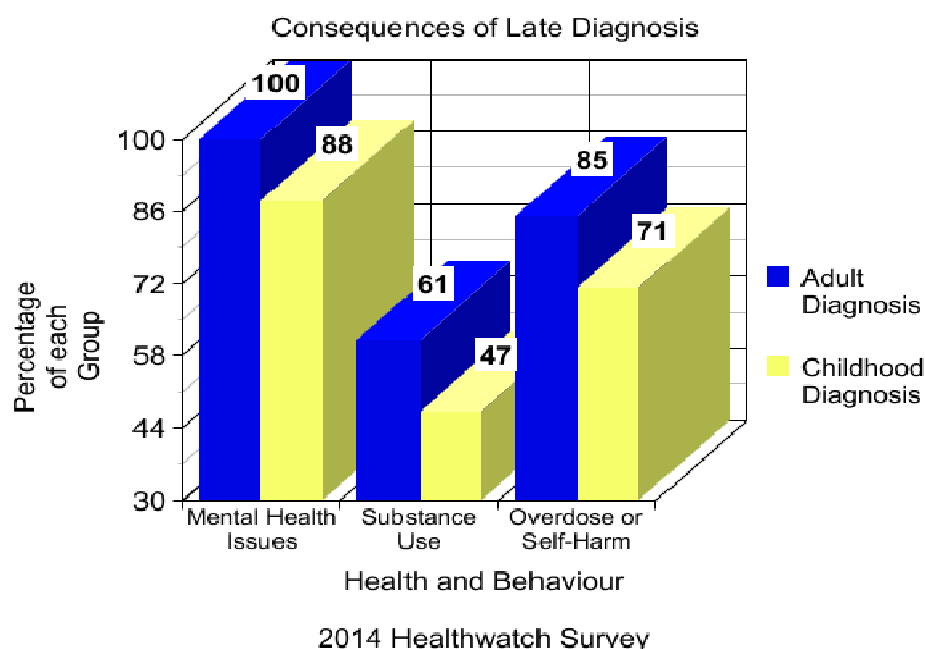
We found with our previous 2013 VLDAS survey that the impact of late diagnosis of ASD in mature adulthood can be devastating. This was also evidenced in the graph below. Autonomy is frequently asked to support adults who are not yet diagnosed so it is probable that there are many more Shropshire residents who are living without knowledge of their neurological condition.

Our survey showed a very clear link between Asperger's syndrome and high ability autism and co-morbid mental health issues. It was quite a concern that **all** of our respondents who were diagnosed late during adulthood had experienced mental health problems compared to 88% of respondents who were diagnosed during childhood. It was also a revelation that only 12% of our respondents diagnosed as children did not have an additional mental health issue as adults (but nearly 90% did). It was interesting that the incidence of mental health problems was reduced by 12% with earlier diagnosis.

It was a concern to note that over **three quarters of our respondents** self harm and 40% use alcohol or cannabis. The graph below also provides evidence that individuals who are diagnosed late during adulthood are more likely to use substances, self-harm or overdose as coping strategies than those diagnosed in childhood.

We feel that more effort should be made to diagnose people as early as possible and for professionals to recognise the link between high ability autism and Asperger's syndrome and mental health issues, self-harm and drug and alcohol use. As one respondent told us after diagnosis that he had a *"feeling of relief – finally it's not me and not my fault. I'm not the problem any more. Should have had someone to talk to me about AS. Someone at the surgery to talk to me, to understand. Hour long [diagnostic] session was a struggle. Knowing someone is there – Wish I had been told earlier. Was angry. Would not have self-harmed. Could have had a better life."*

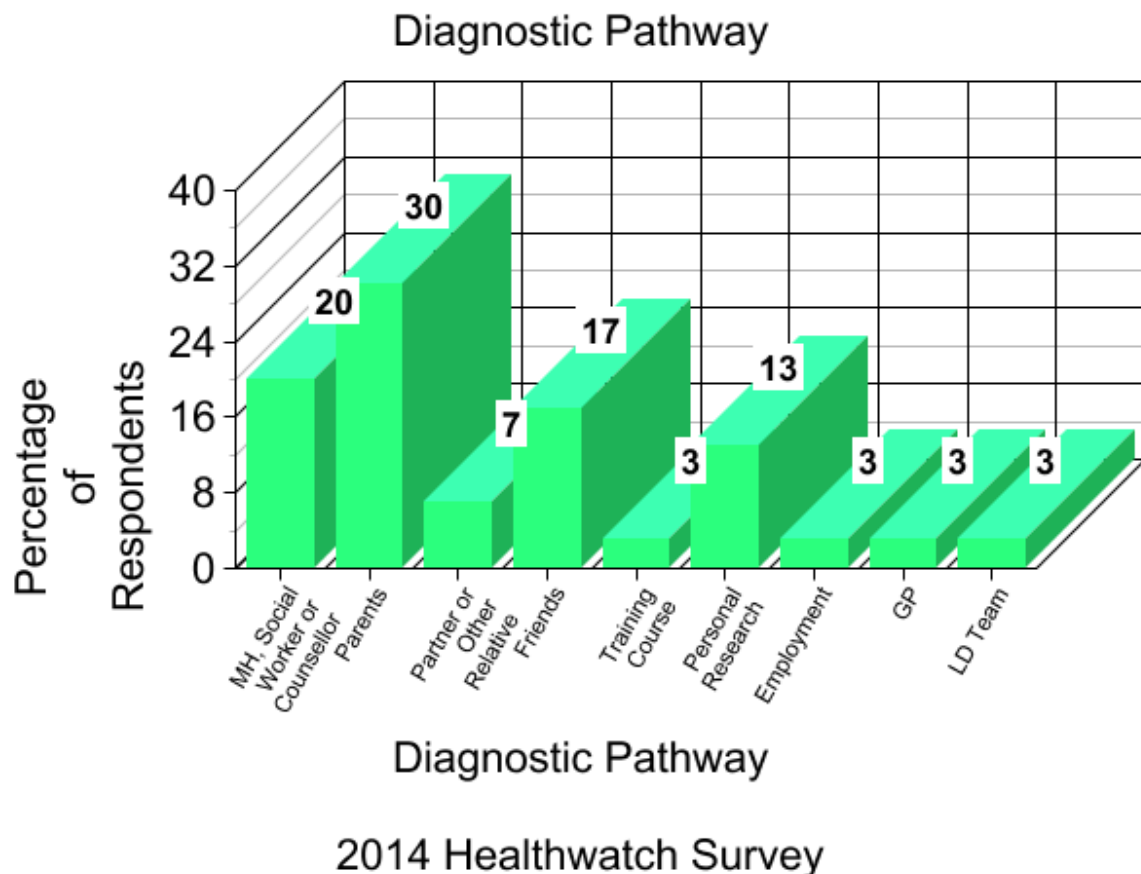
Figure 5: Consequences of late diagnosis



1.3 Diagnostic trigger

Nearly one third of our respondents had been told they had autism and were referred for a diagnosis due to parental concern (30%) especially during childhood. 17% had been told they had autism by friends and 7% had been told by relationship partners or other relatives. It was interesting to note that only 20% of the respondents were identified as being on the autism spectrum via mental health workers, social workers or counsellors. 63% of the individuals in the survey commented that their GPs lacked basic knowledge about autism and as they are often the first step on the medical diagnostic pathway and the main referral route for a diagnosis, it is interesting that just 3% of our respondents discovered their neurological condition through talking with their GP. There is therefore an urgent requirement for more awareness of autism and Asperger's syndrome to be raised in professionals working with our individuals. One mature respondent told us that she "was refused access to a professional diagnosis as I was told I did not have it and it was only stress. I have now self diagnosed."

Figure 6: Diagnostic pathway



1.4 Pre-diagnostic assessment

As our survey has found, 63% of our respondents told us that their GPs lacked knowledge about the breadth of the autism spectrum in adulthood, and only 1 of our members told us that their mental health professional understood the condition; the majority therefore do not and will not easily recognise the condition in their patients. Autonomy Plus has that skill and is able to offer professional pre-diagnostic assessments for these individuals and a report for his/her GP, which can help them along the diagnostic pathway; this can save professional medical time and resources, and is likely to reduce the possibility of subsequent misdiagnosis and unnecessary treatment.

One respondent told us that: *"I mention it and its dismissed. I knew I had AS and every time I asked they said social anxiety or depression. No one mentioned AS. They should have suggested it - the struggles I went through to get my diagnosis. Jumped through hoops. Full training is needed."*

Another respondent told us that as she had been diagnosed with Personality Disorder they did not help her Asperger's as *"they are too eager to shrug it off as mental health"*. A further member told us that the psychiatrist said his self harm was "alcohol related", *"yet I only drank once a month and I self harmed when not drinking."*

One individual told us that the "[GP] did not believe me.... I'm not assertive..... They did not suggest I had it but accepted the [pre-diagnostic] letter from the specialist."

Recommendation

We feel as our respondent stated above in section 1.2, that there should be a peripatetic autism specialist available to attend every GP surgery. We also feel that there should be an Autism Champion at all surgeries and all GPs should have training in recognising the condition - they need to ask the right questions (see Appendix Talking to the GP) and accept the spectrum and diversity of the condition. They need to believe their patients when they think they may have it, and not "fob them off" as one respondent stated. They need also to know the legal rights for patients to request a diagnosis – even if they may have an already diagnosed mental health condition - and should know exactly where to refer patients for a timely medical diagnosis. They should also have details of support and social groups etc for the individual and family members/carers and provide them with an information pack.

We also feel that due to the fact that so many of our respondents self-neglect and have self-harming issues and problems with identifying pain and ill-health without support from another person (see 3.2 3.3) that they too should be offered a yearly health check-up and either carer/family or autism specific advocate support to attend one.

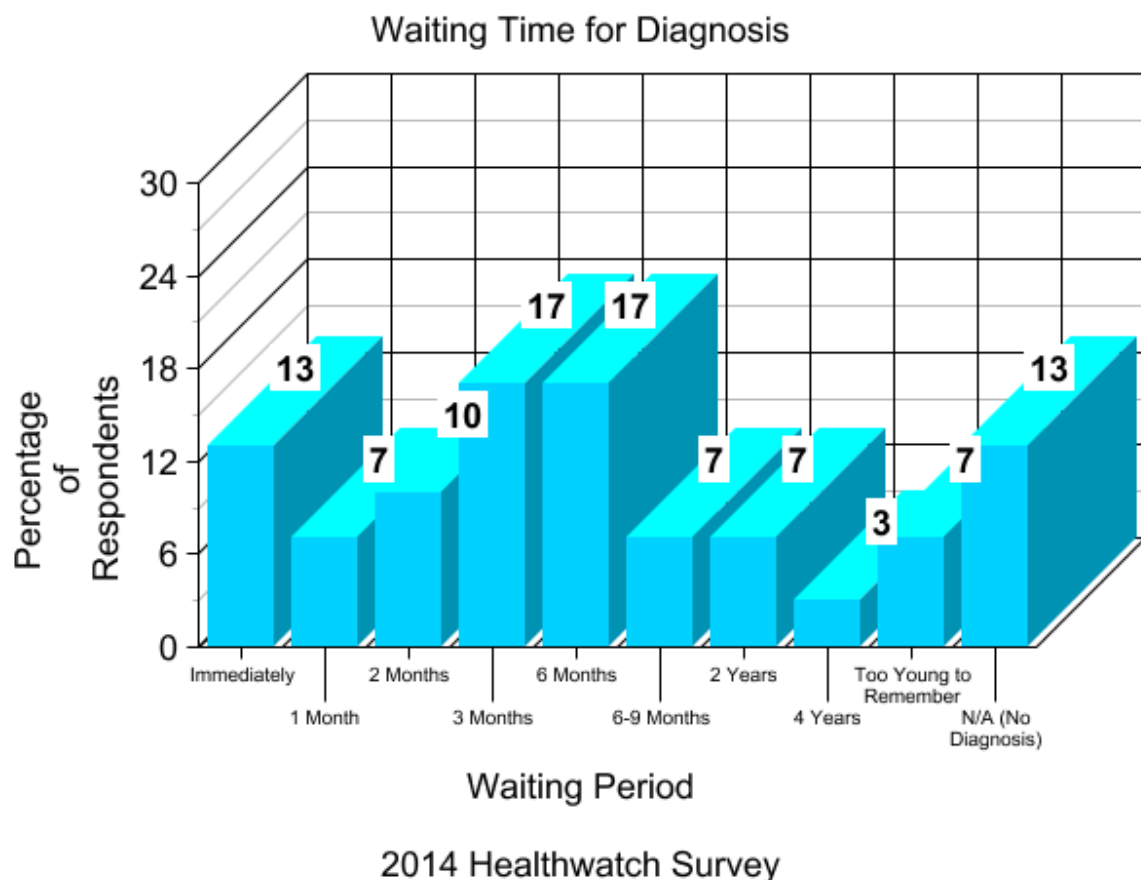
1.5 Waiting period for diagnosis

We discovered that the median waiting period for a diagnosis of autism or Asperger's syndrome for patients in Shropshire was six months even for recently diagnosed individuals; this is double the length suggested in Quality Statement 1 of the NICE Quality Standards Q551, January 2014. It is interesting that 13% of our respondents were diagnosed immediately after identification of their condition as children due to the clarity of their issues. This is not as easy for our predominantly late-to-be-recognised adults or children with more complex needs who are not quickly identified as their autism spectrum traits are not clear and dominant – possibly due to a lack of understanding of the variation in the autism spectrum and the fact that it is a variable condition. Some of our respondents were unfortunate to have to wait up to two years, two of our members still have no formal diagnosis and 3% have had to wait four years before they were diagnosed.

Recommendation

We feel that all patients waiting for a diagnosis should not need to wait longer than 3 months for a diagnostic appointment.

Figure 7: Waiting time for diagnosis



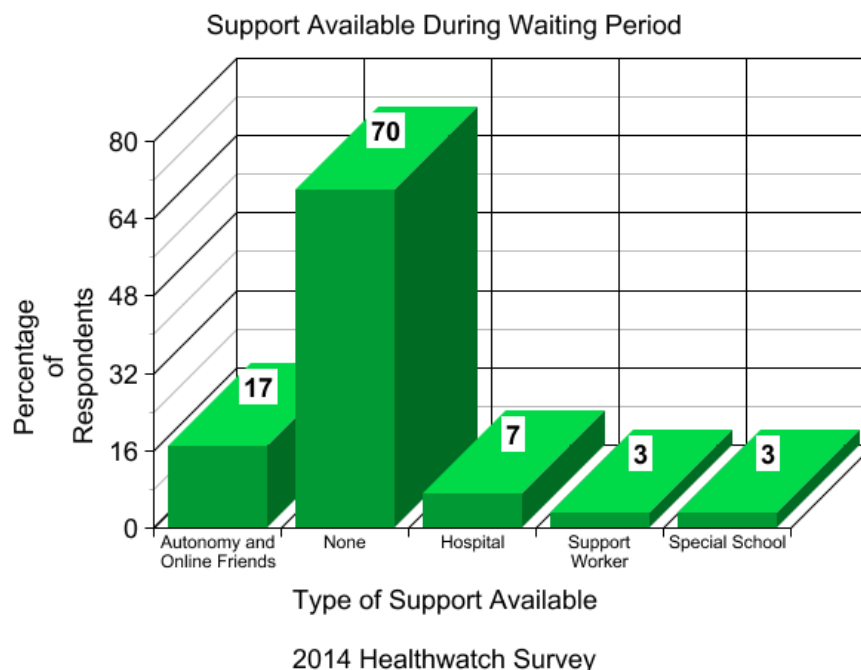
1.6 Support during waiting period

From the work that Autonomy has achieved over the past 10 years, we are aware that a great deal of support is necessary while an individual is waiting for their diagnosis, especially if they have received a pre-diagnostic assessment. This is a challenging and traumatic time for individuals while in “limbo” as they start to come to terms with their condition but have no medical affirmation that that they do have autism. Sadly there is little in the way of funded and statutory support during this critical waiting period in Shropshire, and an over reliance on the individual him/herself, carers/partners or family members. This can be a very confusing period for people who know they are different and probably on the autism spectrum but do not yet have the closure that can occur with a medical diagnosis. Unfortunately a **massive 70%** of our respondents told us that **they had received no support whatsoever while on the waiting list**. Our fortunate respondents discovered Autonomy’s self-help and social groups or the NAS social group which offered essential professional and/or peer support during this critical period.

Recommendation

One respondent on the waiting list simply wanted *“someone to talk to and to stop in and visit. To care about me. There was no one there for me.”* We recommend that all patients on the waiting list for a diagnosis should have professional autism specific support or advocacy provided during this period and that they and family members and carers are referred to self help groups e.g. STACS and have access to peer or professional mentoring.

Figure 8: Support available during waiting period



1.7 Awareness of Social Care Access Rights

According to the Autism Act 2009 and the National Autism Strategy 2010 adults with autism “can expect to be offered” a SCA on diagnosis regardless of IQ”, and those who already have a diagnosis have a right to request a Social Care Assessment (SCA) on the basis of need. In our survey of Shropshire adults with autism and Asperger's syndrome, we found that all but 3 of our respondents are not aware of these rights and nearly two thirds of our respondents (63%) said they did not know what an SCA is, even some who have actually had one.

When asked whether they were offered or even told about a Social Care Assessment after their diagnosis, 83% of respondents said it was “not mentioned at all”, “nothing was offered”, the diagnosis was made, they were dismissed and had no way to request one. Every adult member who was diagnosed had been told he/she had Asperger's syndrome or autism but it seems that the clinicians did not discuss eligible needs, possibly due to the fact that Asperger's diagnosis was normally carried out through our patient services linked to the Learning Disability Team which is a service for patients with IQs of less than 70, and the diagnostic process normally did not explore additional or co-morbid mental health conditions. The right to a referral pathway to social care was therefore not mentioned or discussed. As such, 83% of respondents who received a diagnosis as adults, felt that their diagnosis excluded them from accessing services rather than a pathway to access them; this is therefore proof that most people with autism who reside in Shropshire are not aware of their legal rights to be assessed, being told of their rights to be assessed or even given an opportunity to do so.

The survey also showed that only 10% of respondents told us they received an SCA when referred to services. Those who had an SCA had either fought to have one through the Mental Health Teams or via a referral to People to People, or had one as a matter of course as a result due their perceived or actual IQ after a referral to the Learning Disability Team.

There is often confusion with regard to the difference between Care Plan Approaches (CPAs) from Mental Health Teams, which provide a treatment program and an entitlement to an SCA. In many cases a CPA is used or referred to by the Mental Health Teams as an SCA when they are actually very different procedures. 7% of our respondents told us they had a recent CPA.

Recommendations

We therefore recommend that once diagnosed, adult patients with autism and Asperger's syndrome should be verbally told of their rights to an SCA after diagnosis, or to request one on the basis of need and also given a post diagnostic pack with the information on the service and contact details provided.

Their family members/carers/partners also need to know about the right to a Carer's Assessment.

We also feel that newly diagnosed individuals should be allocated an autism trained advocate/mentor to help them with access to services, especially if they do not have carer or familial support.

1.8 Post-diagnostic support

It was pleasing to note that 27% of survey said they received adequate post-diagnostic support – namely from the three main support groups, one of which is only for diagnosed individuals; some fortunate individuals had this help from psychologists from LD team based on their assessed IQ, as this team has a great deal of autism expertise. Unfortunately, however, the majority 60% of respondents claim they were not supported properly after their diagnosis. These individuals had a mainstream IQ and they certainly did not see any autism professionals or have a support plan as per the NICE Guidelines Quality Statements 3 and 4. 13% of respondents did not comment.

The (57%) who were diagnosed as children did not get much statutory support except at school; but acknowledged that their parents were given some help. Being understood early on in life has, however, helped many of our respondents to come to terms with having autism and Asperger's syndrome in childhood, and they were therefore more accepting of their condition in young and mature adulthood. Our most 'at-risk' group in the survey are the late-diagnosed individuals who have struggled with their condition for many years and need meaningful, consistent and often intensive post diagnostic support and mentoring, due to often having developed unhelpful coping mechanisms e.g. self-harm and/or the use of harmful substances.

In our experience, specialist post diagnostic mentoring on autism specific issues helps reduce anxiety and stress and boosts self esteem by focussing on the social model of disability - the positives of having autism - rather than the medical model that leans towards it being impairment and linked to secondary mental health issues.

Recommendation

We feel that all newly diagnosed individuals should be allocated an autism trained advocate/mentor to help them come to terms with having Asperger's and to negotiate the often long and complex autism diagnostic pathway, and to help them with access to services, especially if they do not have carer or familial support.

SECTION 2: MENTAL HEALTH

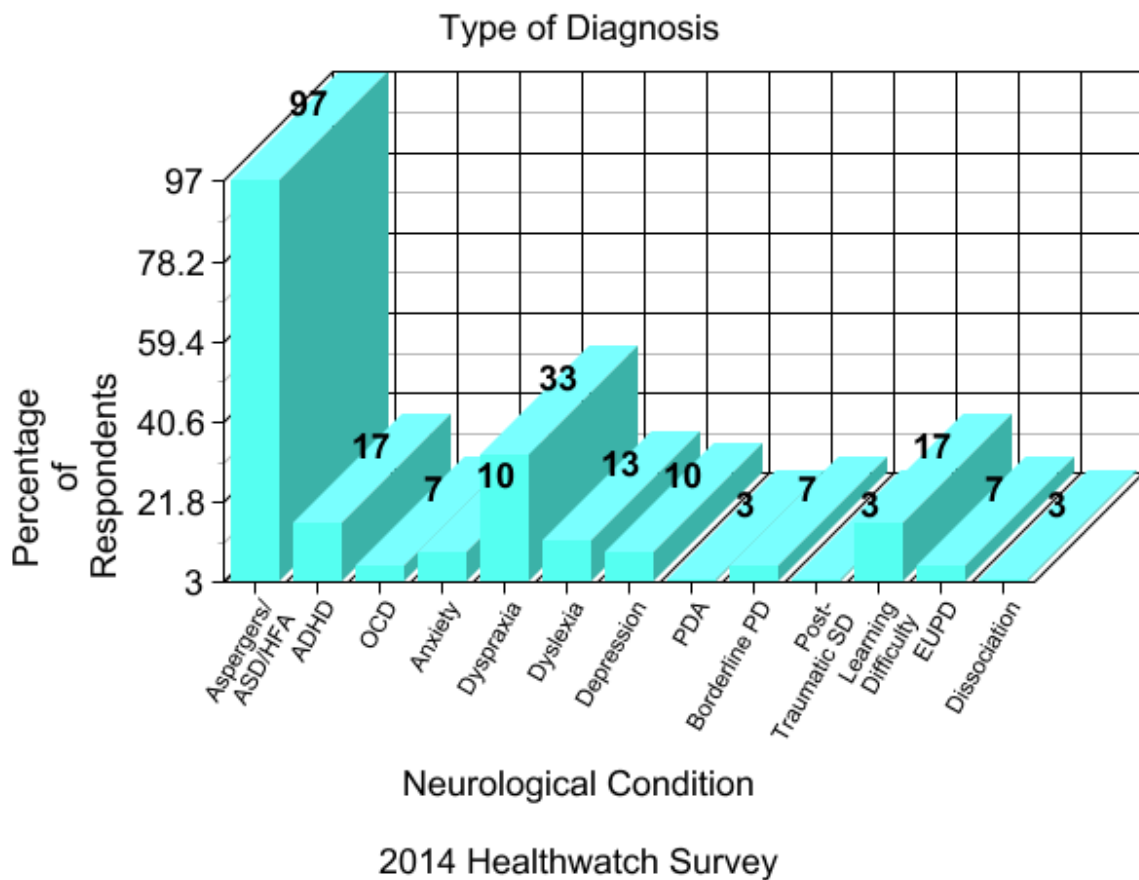
2.1 Neurological conditions and treatments

All of the respondents in this survey have Asperger's syndrome or autism and 28 out of the 30 individuals have a formal diagnosis. The undiagnosed respondent had a positive pre-diagnostic assessment for Asperger's syndrome but had not proceeded with a diagnosis due to it not being recognised via the Mental Health Team; the other individual has "self-diagnosed."

The graph below shows the diagnoses that respondents have received. It was interesting that the majority of respondents have additional issues that are commonly linked or co-morbid with autism and could be a clue to the condition. In our experience these issues could well have developed due to having autism/Asperger's syndrome rather than being separate physical or mental health issues. For example, 63% claim they have experienced, or been treated for stress or eczema; 57% for depression; 63% for anxiety; 30% for Obsessive Compulsive Disorder (OCD); 23% for insomnia; 7% for disassociation; 7% for epilepsy; 17% for phobias; 3% for Tourette's syndrome; 10% for paranoia; and 3% for schizophrenia.

Only 1 of the 30 respondents said that they received a diagnosis which was subsequently quashed. All of our late to be recognised adults have been diagnosed and/or treated separately for these additional conditions before they were assessed for Asperger's syndrome or autism, possibly due to the fact that autism is a hidden disability and can often be confused with or even mask mental illness. It was interesting to discover that the majority of respondents claim to have multiple neurological conditions, typically between 2 and 7 different psychiatric 'disorders' each, yet only 6 of them are supported by the Mental Health Teams.

Figure 9: Type of diagnosis



2.2 Treatment for mental health issues

Our survey respondents told us that they had received the following treatments for their mental health issues - medication from GP or psychiatrist (27%); counselling (30%); or Cognitive Behavioural Therapy or Dialectical Behavioural Therapy, (CBT/DBT,13%). Our respondents had received no statutory or medical treatment or therapy for their autism/Asperger's syndrome, some were told their counsellor "was not an autism specialist" and few adjustments were therefore made to the mainstream treatment programme; the only specialist support they had received had come from the voluntary sector.

Some of our respondents had issues with counselling and that it often did not work for them, or they had not made the expected progress, or that they were forced to attend groups. Some found CBT techniques difficult as they were not adapted for their mindset; some strategies were difficult for our respondents to understand or implement. For a number of individuals, some aspects of DBT were "helpful" – particularly the use of distraction, self-soothing and mindfulness

techniques but not the “helicopter view.”

Out of our 43% of respondents who had counselling/CBT/DBT many told us that they were “challenged” by their counsellors, which is common in some therapy sessions. Two respondents told us about their experiences of being given tasks that were beyond their capability and which did not take into account their social difficulties due to with having Asperger’s syndrome and which show a clear need for awareness training:

One lady had never driven to her session alone and without her SATNAV. Her task was to drive to the next counselling venue on her own and without a SATNAV and if she got lost she was to ask a stranger for directions! She refused due to extreme anxiety about talking to strangers and the sessions were subsequently abandoned.

A gentleman was asked to try to go on a bus as much as possible. He was told by the counsellor that he must not wear his headphones or listen to music while travelling, *“in case a person on the bus wanted to talk to him.”* The respondent became so anxious that he struggled to go on the bus from then on and the counselling task was not achieved.

Recommendations

There is a great need for autism specific awareness training for staff in Mental Health Teams and counsellors. To increase success with these interventions, adaptations and adjustments must be made for people with autism and Asperger’s syndrome when accessing therapies designed for mainstream individuals due to their different cognitive style. Challenging them may be counter-productive. Some will need to be supported in 1-1 situations due to problems with group work. Tasks must be realistic and must also take into account the social issues of having autism; eye contact must not be forced and technology not dis-allowed for social reasons. It is also important to remember that the fact that individuals on the waiting list who have not yet received a formal diagnosis may still have autism spectrum conditions; it is essential that these must be taken into account in any therapy.

2.3 Treatment in mental health (psychiatric) hospitals

The majority (60%) of our respondents told us that they have had no inpatient mental health treatment, 20% (1:5) have been admitted to a mental hospital on voluntary section; 3% were admitted on a mandatory section; 7% received out-patient psychiatric mental health support; and the remaining 10% did not answer this question. Those who have had psychiatric support were not convinced their psychiatrist understood their condition. One respondent told us that her psychiatrist was *“too fixed on my meds [medication] than on therapeutic input.”*

Two of our respondents told us that they “got worse in hospital”, and both tried to kill themselves there, and both nearly succeeded.

One told us: *“Did not fit and had to be with others more ill than I was. A really weird environment. They don’t listen to me....”*

“I needed to go out and have a walk and kept trying to go out to get away but they did not trust me and so I would escape and sneak out and then be away all night and then the police were called

“If I did not eat I was not helped – I was not allowed to eat in my room. I had to eat in the dining room with others. I was told off when I did not eat or just left. No consistency. I don’t like eating around people especially those I did not know.

“I would ask the nurse for someone to talk to and they would say yea and then no one would turn up. I could only get attention and have someone to talk to it I did something wrong. It made me worse. Before I went in I did only superficial cutting but in hospital I cut much deeper as my light cutting was shrugged off as not enough. Comments like I’ve seen worse. I learned to burn myself too with lighters as they are easier to get hold of than knives. Sharpener blades were smuggled in – sneaked off and bought paracetamol and then took them.

“I was accused of dressing inappropriately too as I had shorts on. I can’t stand the heat. I am hyper sensitive to heat and sound. Buzzers went off when things go wrong – kept ringing in my head for hours afterwards. Had noise cancelling headphones to block out the noise.”

Another respondent told us *“they [the staff] did not have time to talk to me and I ended up trying to kill myself from frustration as they were too busy and thought I was a nuisance.*

We asked what would have helped and our respondent told us:

“Talking to me, listening to me, understanding Asperger’s, I was bored. I used to wait for my food and sleep. Used to read magazines and go out every half hour for a cigarette and meet and chat to the other patients. Having a smoke was better therapy than being in the ward.

“One nurse told me “I wish you would not self harm as it hurts me to see you do that” I have Asperger’s – it made me want to self harm more!

“My care was too medicalised – too mental health. Not supportive. Nurse based.”

NB. The full case studies on patient experiences of psychiatric inpatient care are in the Appendix.

2.4 Substance use and misuse

We were interested to see if our respondents used substances in order to cope with having autism/Asperger's syndrome as we found a correlation between this and our later diagnosed individuals in our 2013 VLDAS survey. Most of our respondents (53%) told us that they use prescription drugs as administered by their GP or psychiatrist but it was a concern that one third (10 out of 30) of the respondents told us that they used prescription drugs but not as prescribed by their doctor - which could well be a health risk leading to overdose.

Conversely, one respondent told us that he was *"prescribed medication for anxiety, but was too anxious to take it, the thought of taking it made the anxiety worse."* His condition remains untreated.

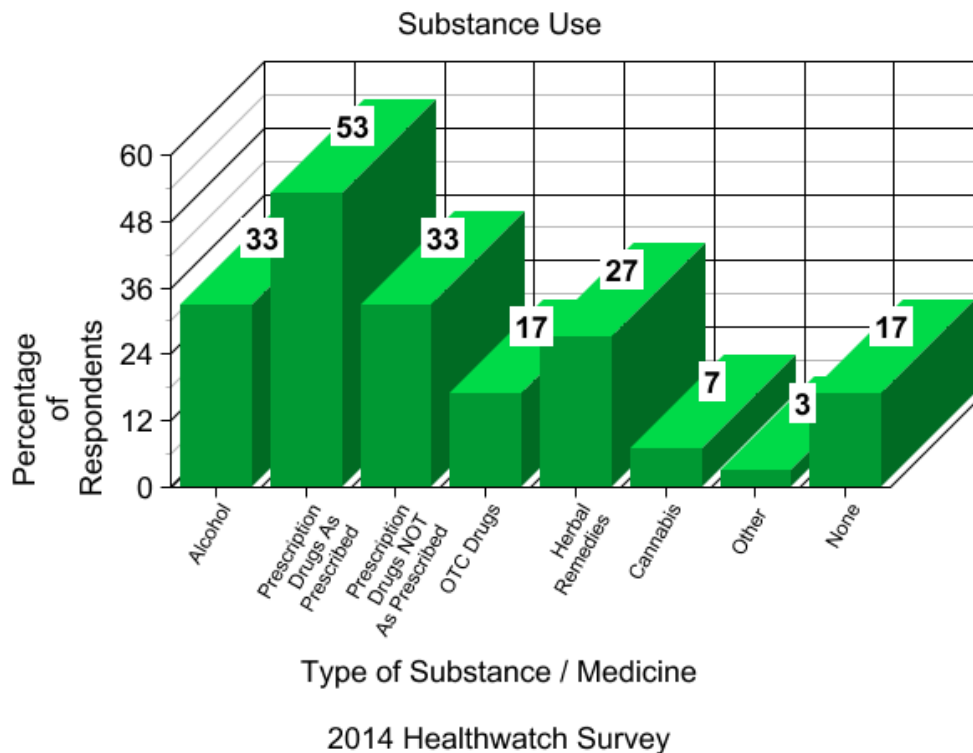
One third of respondents told us that they use alcohol to cope socially and in life and that they drank too much on occasion but also thought that they drank within guidance limits. It was certainly true that our younger respondents and those with an earlier diagnosis tend not to drink as much alcohol as our older respondents and those with a later diagnosis.

One individual told us that *"drink took away the anxiety. I worry about saying or doing the wrong thing so drink took the weight off me, I was not to blame then. My meds don't help me now."*

Our survey found that 17% of our respondents take over the counter drugs from chemists, typically paracetamol and other pain killers. 27% of respondents use herbal remedies such as St John's Wort for depression, and valerian for insomnia. Two of our respondents find oat aveda is helpful.

We also found that 10% of the interviewees said they used cannabis or other illegal drugs and they tended to be the late to be diagnosed individuals. The 17% who stated that they do not use any of these substances at all and never have done were more likely to have been diagnosed during their childhood.

Figure 10: Substance use



2.5 Drug and alcohol treatment and support

It was interesting to note that two of our thirty respondents received statutory support for their use of alcohol or other substances and both individuals said the treatment was unhelpful as it involved attending groups and following a mainstream programme that was not adapted to their autism/Asperger's syndrome.

Recommendations

There is a great need for autism/Asperger's syndrome awareness training for staff. To increase success when using mainstream therapeutic interventions, practitioners must be aware of our patients' different cognitive style, and prepared to make adaptations and adjustments to the programmes. Some patients will need to be supported in 1-1 situations due to problems with group work, and staff must be alert to the fact that many not yet diagnosed individuals who use substances may well have autism/Asperger's syndrome, and that there must be a clear referral pathway for them to access a diagnosis.

2.6 Self-harm

It was alarming to note that nearly three quarters (73%) of our respondents told

us that they have self-harmed in the past and a great concern that 53% state that they are still self-harming. This is worrying when the majority of our respondents are not under the care of any mental health service. Our respondents also explained that self-harm - biting, head banging, scratching, hair pulling, cutting, picking, burning etc were often a way of coping with the sensory overloading issues that are common in autism spectrum conditions.

2.7 Perceived suicide risk

Having sadly had one Autonomy member take his own life, we were keen to ask our respondents about their own self-harming and suicidal feelings. We are aware that some people on the autism spectrum can use the word “suicide” inappropriately but this did not mean that they were not prepared to take their own lives. We were very concerned when 73% of respondents told us that they had felt suicidal in the past and 53% told us that they often feel that way at the current time. Some had stockpiled medication and others had practical ways planned for taking their own lives, and one respondent told us of two recent attempts he had made to hang himself; and two mentioned ligaturing themselves; our evidence also shows that our respondents do not seek external help or support, and those who do so are not always understood by the services they access. We are also aware through the work we do with our members that some voluntary or charitable organisations do not have the training needed in supporting people with Asperger’s syndrome especially when feeling suicidal.

It is probable that some of our respondents will not be seen as a true suicide risk due to a lack of awareness of the link to Asperger’s syndrome and suicide or that this behaviour is blamed on a co-morbid mental health condition, namely Personality Disorder. National research has found that people with Asperger’s syndrome actually have a higher than expected incidence of suicide and suicidal ideation than would be expected and our statistics show that these at risk respondents are usually not supported by the mental health teams, and none is given autism specific help and support for these issues.
<http://www.medicalnewstoday.com/articles/278678.php>

2.8 Psychiatric treatments

23% of our respondents have had regular appointments with mental health psychiatrists (but not those who medically diagnosed them from the Learning Disability Teams). When asked whether their current psychiatrists understood autism/Asperger’s syndrome it was a concern that only 9% said they did, but we were disturbed to learn that most of those (91%) said that their psychiatrists did not understand autism/Asperger’s syndrome. This is a further major factor in the lack of recognition of autism/Asperger’s syndrome in Shropshire as people with autism/Asperger’s syndrome can have episodes of poor mental health as part of their condition. There continues to be a clear lack of autism/Asperger’s

syndrome specialist support for the Mental Health Teams and therefore a major requirement for training in this area, especially as the Mental Health teams will take on the diagnosis of Asperger's syndrome in Shropshire from the Learning Disability Teams in November 2014.

2.9 Consequences of Late Diagnosis

As identified in the graph (Fig. 5) on page 14, late diagnosis of Asperger's syndrome is clearly linked to previous and additional mental health issues, substance use and self-harm. We feel that this report provides evidence of the importance of an early diagnosis. Being recognised in childhood can be cost effective – it can save staff time, funding, resources and could actually save lives.

Autonomy is aware that a diagnosis of autism/Asperger's syndrome late at any age is important and can make a real difference to a person's life and future, even those in mature years. As we found in our 2013 VLDAS survey, having a diagnosis even late in life can be "transformational" and "life changing."

However positive it may be to be finally diagnosed, our respondents who are discovered late in life have often felt resentment for being misunderstood for so many years and felt that they had lost out on basic opportunities in life which mainstream people take for granted. When they discover their neurological condition, typically after being diagnosed with and treated for one or even two mental health or physical conditions, they tell us that they often feel let down by the medical system and society at large.

SECTION 3: PHYSICAL HEALTH

3.1 Access to GP

All respondents in this survey were registered with a GP and half of them said it was easy to make an appointment and 7% did not answer this question. It is a concern that 43% of our respondents found it difficult to make an appointment which is not surprising considering that many live alone and also that autism is a social and communication problem and appointments tend only to be made via the phone or face to face; it is a well known fact that people with autism can tend to struggle to talk to people they do not know well. In our survey, one individual found that the practice manager was more approachable than the GP and another member asked her pharmacist to liaise with the surgery on her behalf.

When asked whether they found it easy to access their GP's surgery, 80% said it was easy but 20%, which is 1:5 of our respondents, found access challenging. The main reasons were the phone system, time keeping, communication issues e.g. having to talk to staff members, sitting close to strangers, being near noisy or sick children or sensory issues to do with our respondents' autism spectrum conditions.

One respondent told us that he has to *“go there with a carer. Sometimes I get nervous and jumbly and have to explain again...”*

Another individual told us: *“I walk in as I can have help. I can't do phone calls – unless support worker with me. Hear the voice and put phone down as I just can't do it. Stranger or robot?”*

Another respondent told us: *“I get worried about talking to strangers. I like the appointments to be on time. I don't like hanging around. I've waited for 40 minutes. I get irritable and have to walk around and look at magazines. I count the patterns on things.”*

Another stated that the *“surgery needs to have no children or babies running screaming shouting or I will shout and scream and bang the door. I can't get away from the noise. It physically hurts me – like a pin sticking in my ears.”*

One respondent is beginning to challenge himself and use coping mechanisms when going to the GP surgery and told us: *“I don't have a problem with it. I do try to challenge myself. So I will still go if it's noisy and crowded. Ok waiting but not long times. Use phone if bored.”*

People with autism and Asperger's syndrome also struggle with flexibility issues as part of their condition. Our survey found that there was a lot of inconsistency with regard to the GP surgeries as they were run in different ways; some called

out the patient's name and others scrolled it out on the board. It would help our members if there was more constancy within the primary care system.

See Appendix for more stories on Access to GP

3.2 Awareness of ill-health

Our survey also showed that 35% of our respondents often lack awareness that they may be feeling ill and that they have a health problem, and due to their sensory issues (and a “disconnection” between their physical bodies and minds) so they need help identifying the source of their issue and often rely on a carer/parent or friend to help them recognise this. The problem is also exacerbated by the person's tendency not to be able to express their issues using appropriate right words – a common problem with people with autism spectrum conditions.

A greater concern is that 62% of our respondents said they would not ask for help when they are not well. Participants also gave us the following reason for not asking for professional medical help, which were a distrust of the NHS and not wanting to go out of doors.

One respondent has found an innovative way to avoid talking to strangers and to have help with understanding when she is ill: *“I can phone the pharmacy though – and they contact the surgery for me which helps a lot with my prescriptions – I trust them. I often ask the pharmacist if I am unwell – use him as a decision tree and he will tell me when to contact the GP”.*

Several of our respondents mentioned that they experience pain but they may not know where the pain originates and why. As one lady told us *“she accepted it as there was a slow build up and did not know it hurt until it stopped hurting.”* Our frequent self harmers also have a high pain threshold. One individual told us that *“When I self harm I like to see the blood and don't feel pain. Takes quite a while for me to feel it.”*

It is therefore important that GPs are trained to understand people on the autism spectrum may not feel pain in the same way as typical people, and they could cause severe damage to themselves without any acknowledgement that this is the case. One member had a huge gash in his leg but it had become septic before he told his mother about it. One respondent told us that he *“should have gone but did not mention things for 4 months. I was worried. About something underneath.”*

Another respondent told us that *“I used to be called a hypochondriac as I was ill so much. Now they blame me mental health for it.”*

NB. The full case studies on patients' awareness of pain and ill-health are in the Appendix

3.3 Tendency to self neglect

We asked our respondents about eating and diet; 90% of our respondents knew what a healthy diet was and the important foods to eat; when asked if they ate a healthy diet, only 47% said that they did and 53% told us that they did not eat any of the healthy foods or have a balanced diet. Quite a few mentioned eating meals only about every three days. One respondent stated that the “convenience” of the food was an important factor when eating it.

We asked if our people with autism and Asperger’s syndrome had a tendency to self neglect, especially if living alone. 7 of our respondents told us that they were aware that they self neglected but there was clear additional evidence of this problem throughout the other survey answers our respondents gave.

Evidence of self neglect included not seeking help and support, or not being able to access help and support for: ill-health and pain issues, ignoring or not being aware of pain and illness, self-harming, substance use and misuse, poor hygiene problems, changing clothes, poor oral hygiene, eating too much, comfort eating, not eating or drinking regularly etc. Others cited depression, anxiety, motivation problems, disorganisation problems, coping with change, OCD, and the time spent on their special interests, music, the internet or computer games as the reasons so many did not care for themselves appropriately.

One respondent told us *“I over eat. I comfort eat. Am greedy. I like biscuits. I used to be told to wash as I used to smell of BO. My carer tells me what to do now.”*

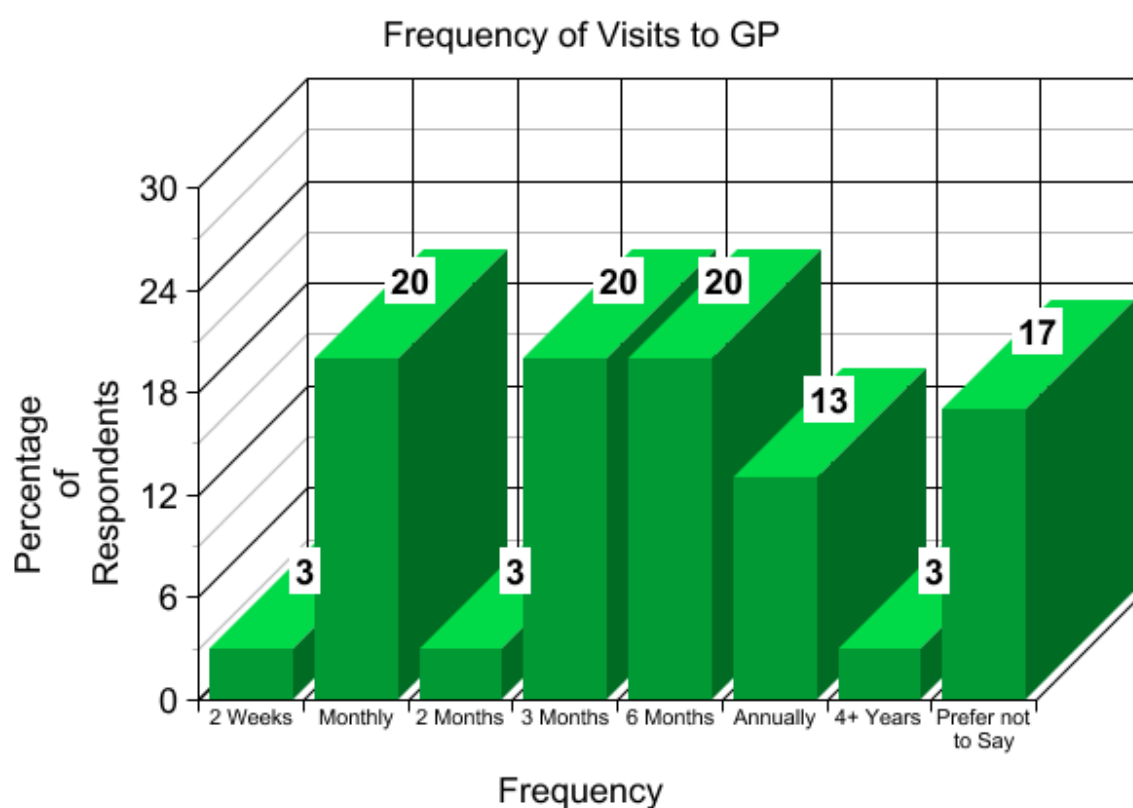
Another told us that he did “not shower” and was “sporadic” – “binge eating for a day then 3 days with little food.”

A further respondent told us that he does not eat or wash when feeling down –*“I have to be motivated as A.S. means it has to be right for me to eat texture flavour etc. I’m over weight and don’t deserve food. Have had days without eating – but not so much now. Can binge.”*

Our survey clearly shows that our respondents are at great risk of neglect and self-neglect; we are pleased to have been notified by the National Autistic Society that they have been successful with their recent campaign to highlight deficiencies in the 2015 Care Act, with regard to this issue for people on the autism spectrum.

NB. The full case studies on patient self-neglect are in the Appendix

Figure 11: Frequency of visits to GP



2014 Healthwatch Survey

3.4 Frequency of visits to GP

We wished to investigate how often our respondents visited the GP each year. In the graph above it can be seen that the median frequency of our respondents' appointments to their GPs was every six months. One of the 30 respondents visits his/her GP every two weeks; and at the other extreme was a respondent who visits his or her GP every four years.

As previously noted we found that some of our respondents are reluctant to visit their GP due to a combination of access issues, sensory and communication problems, time keeping and waiting time problems, phone difficulties and a lack of support or advocacy.

We asked our respondents if their GP understood autism and were quite concerned that only 30% of our respondents believed that this was the case. One of our patients told us that in her opinion, "certain doctors are unsympathetic and do not have sufficient understanding of Asperger's syndrome and very little interest in increasing their understanding."

3.5 Relationship with GP

It was good to know that 60% of our respondents said they found it easy to talk to their GP but about 20% had a parent or carer with them at all appointments. It was a concern, however, that the rest of the respondents (nearly 40%) found it difficult to communicate with their GP and this shows a great need for GP training in this area. A typical statement from our respondents was “no one understands”, or “the majority [of GPs] don’t.”

One respondent told us: *“GPs have a lack of sympathy and a lack of understanding. They lack interest and feel no need to improve their understanding to benefit their patients. This applies to all bar one GP at the practice.”*

Another respondent told us *“I get the feeling she's been told about it but still does not know how to act with people on the spectrum.”*

One individual told us, *“I don't think so – it's a bit of an excuse. Slightly weird – not full understanding.”*

As mentioned above just 30% of the respondents believe that their GPs have an understanding of autism. Our respondents told us of several incidents where the GP asked his/her patients what he/she wanted him/her to do for him/her. This was confusing for our respondents as the GP may well be expecting the individuals to have insight into their issues and to give information to the GP due to the fact that GP may not know them well. People with Asperger's syndrome and autism have “theory of mind” difficulties which will affect them in these situations; they may expect the GP to lead the questions as he/she is the qualified health professional, and the Asperger's individual is purely the patient. Those who have thoroughly researched their conditions may well be disappointed by the GP's reactions to their concerns. These problems tie in well to our questions (see above) on understanding when you are feeling unwell and asking for help when you are ill where we found that the majority of our respondents said they often needed others to tell them when they were ill and that they often did not ask for help when ill.

Several of our respondents mentioned that the GP would ask them “What can I do for you today?” Our respondents often found this question to be vague and confusing and said they would prefer their GPs to ask specific questions about their health eg “What have you come to talk to me about?” or “What do you think is wrong with you?” Or “What health problem can I help you with today?”

Some respondents told us that they are easily be distracted by their GP's questions too, meaning that they could discuss a much less important issue rather than the serious one they need help with. Several respondents mentioned that they talked about the wrong subject with the GP - which was evidence of a

probable wasted appointment. One major example of this was when a respondent visited his doctor to talk about chest pains but his GP asked him about how his knee was, as that has been a longstanding issue for him. The patient got distracted by his doctor's focus on his knee and talked about it but left the surgery without mentioning or receiving any advice about his chest pains which could have been extremely serious. The result was that two appointments were necessary instead of just the one.

One respondent who had additional mental health issues did not even make an appointment to see the GP as it was "pointless" and told us: *"I have lumps that I want to show the GP but he will probably say its mental health. Or another excuse..."*

Another respondent stated that *"When Mum's there then she helps to keep me on track. On my own I forget to tell him what I need to tell him. I get a memory block and talk about wrong things. I even forget when he asks me if there is anything else he can do for me. He should just ask me what's the problem, and what can I help you with today. That would be helpful. I would then not get side tracked and go home without telling him and might not need my carer. I need to write it down too as that would help."*

Another said that she uses numbers as a pain or illness calculator and this helps her mother and carer to find out if she is feeling unwell – but also explained, *"I will answer 'how are you?' With 'I'm fine thanks,' as that's what I've been told to answer. They have to ask the right questions to get the right answer."*

Another of our respondents mentioned that just talking to other patients in the surgery can be difficult: *"the surgery sets my anxiety and OCD and I get anxious when there is someone who knows me or the family. They ask me questions and I'm embarrassed. I'm thinking of what to say about my illness with the GP and then I get side tracked and forget what I want to tell him."*

NB. The full case studies on patient experiences of their Relationship with GPs are in the Appendix

Recommendations

Our respondents would prefer their GPs to ask short specific questions about their health e.g. What have you come to talk to me about?" or What do you think is wrong with you? Or "What health problem can I help you with today?"

Respondents told us they easily got side tracked so need GPs to wait and ask them about today's problem, rather discuss a previous condition.

If asked “How are you?” they may answer “I’m fine thanks.” Respondents tell us that GPs must ask the right questions to get the right answers.

One of our respondents mentioned that numbers can be used as a pain or illness calculator to find out how unwell a patient is feeling – this strategy could be used by GPs.

As many of our respondents mentioned not coping with long waiting times, individual strategies or reasonable adjustments will need to be put in place for those individuals and patients who struggle to sit in the waiting room with other people nearby.

Mental health can tend to be a focus for GPs who also need to have training in awareness of co-morbid conditions and how they are affected by autism, and visa versa.

There also needs to be some understanding that people with autism and Asperger’s syndrome may function well above mainstream cognitive ability but will often have major gaps in their learning and understanding and need support from others. As stated by the NAS in their guidance to GPs in our Appendix – “GPs need to be aware that autism and Asperger’s syndrome are often described as a hidden disability because you cannot tell that someone has the condition just by looking at them or even when talking to them in a 1-1 situation. People with the condition also rely heavily on other people in their day-to-day lives in a way that you might not expect, given their apparent intelligence or independence, or them stating that this is the case.”

NB. This is more evidence of the need for our respondents to have advocacy and support.

3.6 Vaccinations

Half of our survey respondents think they are up-to-date with their vaccinations (whether they are or not). Two respondents (7%) said they were not up-to-date with their vaccinations and the remainder of 43% didn’t know whether they needed additional vaccinations.

Only 23% of the people interviewed said they had received a flu injection; 73% of respondents said they had not received a flu injection and had not been offered one and one person was not sure whether s/he had received the vaccination or not.

3.7 Diet, weight and exercise

It was a concern to us that the majority of the people interviewed in this survey were either overweight (43%) or obese (17%), making a total of 60% of our

respondents with a weight problem. One third of the respondents had a healthy weight and 7% were underweight for their height.

Reasons cited for being overweight included the side effects of their medication (10%), depression and polycystic ovaries. Other reasons were sensory issues to do with food and self neglect which were mentioned by our respondents. When asked about exercise, one third of the interviewees admitted they did not exercise regularly.

We noted that 90% of the people in this survey believed that they understand what a healthy diet is but just over half of the respondents (53%) say they actually find it difficult to eat a healthy diet, yet only two of the individuals (7%) had received advice from a dietitian.

One respondent told us: *"I either don't eat or over eat. GP would not believe me when I said I had not eaten for a week. Graze boxes are helpful. Fridge is empty. I do eat apples."* He was referred to the Eating Disorder Clinic but did not attend the appointment.

Another individual told us that: *I'm over weight and don't deserve food. Have had days without eating – but not so much now. Can binge."*

Recommendation

GPs need to be aware of the food sensitivities and problems people with autism have with eating a varied and healthy diet, with regular food intake, taking exercise and with problems of self neglect. Any referrals for eating disorders, diet or weight support will need to be to staff that have awareness training in autism in order for any support to be effective.

3.8 Alcohol and smoking

57% of the respondents claim to know what the maximum recommended safe limit is for units of alcohol consumption. 13% of the respondents said that they exceed this recommended limit – and they tended to be the mature, later to be diagnosed individuals.

36% of respondents have smoked cigarettes sometime in their lives. Just one of our thirty respondents has vaped using e-cigarettes.

3.9 Health check-ups

Due to the fact that so many of our respondents said that they struggle to identify pain and ill-health, (see 3.1, 3.2) we asked if they would attend a yearly health check-up if offered one. Our 5 eligible respondents are already given access to one through the MH or LD teams, and the 40+ year old respondents had already

attended a "routine" GP health check, but would have preferred a more thorough one. We found that 22/25 our non LD/MH supported respondents in this survey said they would have one and more especially, if supported to attend it. Some added comments eg it being "a good idea," "very beneficial," giving "peace of mind," "keeping things on track" and "in case I miss something."

3.10 Cancer screening

We noted that only 30% of our respondents have had screening for cancer but they were both male and female and the median age was 31-35. The lack of uptake may be due to the age difference at which male and female screenings take place as several of the respondents believed that they are not old enough to benefit from regular health screenings despite being over 21 years old and some women admitted to being sexually active.

Another reason for little engagement may be due to a lack of understanding of the importance of such interventions or the fact that they involve sexual organs when many of our members struggle to engage in any physical relationships. When screening was discussed with our respondents they mentioned they need to be given more information about the subject and the benefits of the procedures rather than just being sent letters or flyers in the post that can cause anxiety or which they do not understand. Some women mentioned their sensory issues in intimate areas and being touched by strangers as being a further issue.

Some female respondents told us that they will attend screening appointments on their own but as so many said that they needed or had support just to access the GP surgery so it can be assumed that they would also require help to attend a screening appointment. It is therefore likely that our respondents would attend more screening appointments if they had familial or advocacy help. Although just 30% of our respondents have screening for cancer, 87% said they would have regular screenings if they were offered the necessary support.

People with Asperger's syndrome and high ability autism have a diagnosis of autism but without a learning disability. They may be more able intellectually but will still struggle with many or most of the issues that people with autism and a learning disability face, so this should not preclude them from having a health check for the same reason.

3.11 Dentistry

It was quite unexpected and also alarming to find that a major health inequality for our respondents was consistent access to a dentist as there is a clear link between oral and physical health. 70% of the adults in our survey told us that they were registered with a dentist but 30% were not. We asked how often they

visited the dentist and it was a further concern to hear that just 47% of our respondents visited their dentist regularly, and 53% said they did not.

Some of the reasons cited by our interviewees for not accessing dentists are cost of appointments, pain and sensitivity issues, lack of advocacy or support, a lack of trust and being closed to the service. Many of our respondents told us that they struggle with major sensory issues due to having autism and the typical dentist surgery is full of bright lights and involves a lot of close intimate contact in sensitive areas of the body, plus similar issues (discussed above) that are experienced by our respondents with access to the GP. Some of our respondents rely on brushing their teeth well and the fact they are not in pain to avoid going to the dentist – but we are also aware that most of our respondents have impaired recognition of pain and ill health due to having autism, (see above) and may not be aware that they are possibly building up future dental problems.

Many of our respondents live alone and many have co-morbid dyspraxia and ADHD which can affect memory and organisation skills; dental appointments are often made 6 months in the future are likely to be forgotten. The fee structure was also cited as a problem due to the cost of attending an appointment, as 22/30 of our respondents are not employed, and not all are able to claim the benefits that allow free dentistry.

Anecdotally, more of the individuals in our survey said would visit their dentist regularly if dental check-ups were free of charge, if the dentists were aware of their sensory issues and these were addressed, if there was understanding about why they may miss or not turn up for appointments, an easier way to get back on the register, and advocacy support to attend them.

Our respondents mentioned that dentists will often only treat patients who attend regular appointments and those that do not will often have their file closed and have no follow up – this has happened to 30% of our respondents – one of whom needed intensive hospital treatment due to the state of his teeth and others who have lost teeth, so advocacy support could help with this.

These are some of our respondents' comments about the dentist:

"My fillings are often falling out and I'm not motivated to get them sorted. They don't do a good job."

"I don't have regular appointments anymore as I had not gone to some of them so they took my off the list. I brush my teeth well though."

"I had not been since 17. My teeth don't hurt so I carried on. I [then] needed emergency dentist but was refused so could not see one. I phoned and was abusive and I've not seen a dentist since January as now banned. I will try to get another one."

“One time I did not go to the dentist for 11 years. I do go now when they send me a letter. I did not like the dentist before as she did not understand then I moved. I went off them. Then they did not send me appointments. I went to dentist and filled a form and then it got silly as I did not know what to do. I had to take antibiotics. I did not sign up to the dentist. I put it off. I did not see the new one for a year. I cancelled appointments. Then I had bad toothache and had to have hospital treatment and some teeth out 10 months later. My friend told me to go to the dentist.

“I stopped going as he was lecturing me about cleaning my teeth and I argued with this. Now it's clear and straight will go. I know what I should do but struggle to do so due to motivation. I need to be prompted. How often should I do my teeth? He prescribed me toothpaste so I'm more likely to use it. I'm doing it more regularly.”

NB. The full case studies on patient experiences of dentistry are in the Appendix

Recommendations

It is recommended that dentists are aware that their patients have autism or Asperger's syndrome and undertake specific training in the condition especially the areas of sensory sensitivity and the fact that although intellectually bright, their patients may have gaps in their learning or understanding. It would also be beneficial if any co-morbid ADHD, dyspraxia or mental health issues are recorded as well, as the impact of these conditions on patients with Asperger's syndrome and autism.

Any non-attendance or cancelled appointments should be highlighted and followed up as these individuals can tend to be vulnerable to self neglect. Patients with these conditions may need advocacy, or family or carer support and help to organise themselves to attend appointments, so permission may need to be sought from the patient to involve them in the process.

Dentists should be aware that their patients with Asperger's syndrome and autism may react badly to criticism or perceived arrogance from staff. Staff who are kind and friendly and gentle will have more success. Patients with autism and Asperger's syndrome will also need clarity with instruction, explanation for the reasons for these instructions and more, repetition, prompting, reminding than their mainstream patients.

3.12 Eye care

28/30 of our respondents claim benefits or qualify for a tax exemption certificate, so can have free eye tests. Our members who wore glasses/contact lenses had more frequent eye tests and were generally satisfied with their access to eye care when necessary. It was a concern that those who did not wear

glasses/contact lenses were not registered with an optician and often relied on the recognition that their eyesight was changing, rather than attending regular appointments. Several respondents are continuing to wear glasses/contact lenses that are not the right prescription for them and, anecdotally, the high cost of glasses or contact lenses was cited as being an obstacle to replacing them.

Several respondents of Autonomy had been assessed for Irlen lenses which they wore to reduce their hypersensitivity. They were very pleased with the service that was offered.

3.13 General hospitals

In our survey, 63% of the adults in our survey had received hospital treatment during the past five years, and of this group, 47% said they had good treatment. It was a concern that 37% said they did not receive good treatment as they felt that they had not been fully understood; the remaining 16% did not comment. One respondent mentioned that he was not helped to the toilet when he was in the ward as he had problems with gaining eye contact with the staff and did not know how to press the call button. He became so desperate that he phoned Autonomy to contact the ward to tell the nurses that he needed help.

One respondent told us that he had not fully understood what the procedure was beforehand but that the hospital staff *“were nice and kind I was sedated. I had to drink some prep stuff and it was yuck and lots of water but I ate food when I should not have had food but I did. I had a piece of apple pie. I did not read the instructions so did it wrong but they understood.”*

NB. The full case studies on patient experiences of general hospital inpatient care are in the Appendix

3.14 Access to out of hours and emergency services

Seeing as many of our respondents have problems accessing GP practices and have issues with regard to self-harming behaviour and identifying pain and ill health, we were interested to note that just 5 of our 30 respondents told us they had regularly sought help from the Ambulance Service, the Crisis Team, had been frequent attendees at Accident and Emergency Departments or had accessed the out of hours primary care services e.g. Shropdoc in the past two years for emergencies.

We asked our respondents how often they had accessed out of hours and emergency services, and the main reasons cited were self-harming - “as pressure built up,” or due to sensory issues and limited coping strategies related to having an autism spectrum condition, anxiety, a cry for help, feeling mentally unwell, mentally “overloading,” feeling suicidal and overdosing.

a) Attendance at Accident and Emergency (A&E)

In our survey we found that one individual had attended A&E 6+ times a year, one person had been there every 2 months – “that regular that I was on first name terms,” – one went to A&E once a month, and one attends A&E when she has self harmed or when the ambulance takes her there.

We were told that staff at A&E *“were not particularly helpful, but not hostile. Lots of waiting in hospital though and that gets me agitated. I’ve left hospital early without signing out cos the staff were too busy.”*

The other four were positive about the support they had had from A&E and that the staff were *“always understanding and kind”, although one individual told us “I was worried I was a burden but they were always sympathetic.”*

b) Ambulances

With regard to ambulances, one respondent had ambulances called out about 4 times in the past 2 years and one stated that she has an ambulance called out at least 5 times a week at the current time. The individual told us that it is accepted that this behaviour is “due to her mental health condition.” At the time of writing the ambulances are still being sent to this individual - about the same time each evening, and for similar reasons and we are concerned that there seems to be no co-ordinated health and social care strategy, no autism specific help or any support programme implemented to support this person to reduce the high number of ambulance call outs.

c) Crisis Team

Our respondents commented that:

“The Crisis Team had no understanding and could not support me when in crisis and suicidal.

“They haven’t a clue. There is a desperate need for training in Asperger’s. They don’t understand. Why is the Crisis Team for people who are suicidal only? Asperger’s people are left out again.

“They try to fob you off. You need to listen more and understand. They seem to think I’m suicidal cos of my [mental] illness when it’s not always the case. It can be triggered by other things and they don’t spend time asking me why I feel that way.”

SECTION 4: SOCIAL CARE

4.1 Introduction to the Autism Act 2009

The main objective of the Autism Act 2009 was to provide the necessary health and statutory support to people who are on the autism spectrum. An important requirement that arose from this legislation is the right to have a Social Care Assessment (SCA) which addresses the health and wellbeing issues of people with additional needs. Full SCAs cover nine areas including health and wellbeing, self care, finance, relationships and social relationships, independent living, emotional health, and medical issues. The mental health Care Plan Approach is a medical programme for service users who have treatable mental health conditions, and is not a full assessment of need. As far as we are aware, only 2 of our respondents who had had CPAs for mental health conditions had an additional SCA. Those who had been supported by the learning disability team or referred to People to People had had an SCA but not a CPA.

4.2 Social Care Assessments

The Autism Act 2009 statutory guidance states that on receiving a diagnosis of autism, adults with autism **should expect** to be **offered** a “community care assessment”, regardless of their IQ and where they are on the spectrum. It also says that carers **can be expected to be informed of their right to a carer's assessment**. 28 of the 30 respondents in our survey had a formal diagnosis of autism and therefore were legally entitled to request or ‘expect’ an SCA, yet only 3 of the group had received them due to a referral to services. Despite it being law for nearly five years, over 80% of our interviewees had no knowledge about SCAs including their legal rights to request one, or to be offered one as standard after their recent adult diagnosis of a developmental disability or even know how to embark on that process. Few carers/partners or parents we offered Carer's Assessment, and none of our respondents had been offered one even if they were also a carer.

A Community Care Assessment is an assessment of need. A Social Care Assessment is also a needs' assessment. There is a bit of confusion as to whether they are the same assessment and the one that our respondents are eligible for. Adding further to the complexity is that now that health and social care services are more integrated, it can also be called a Health and Social Care Assessment.

http://www.adviceguide.org.uk/england/relationships_e/relationships_looking_after_people_e/community_care.htm

<https://www.gov.uk/apply-needs-assessment-social-service>

Formal statutory assessments tend to be carried out by Health and Social Services staff to find out what help and support you need - like healthcare, equipment, help in your home or residential care or with personal care and independent living. The assessments can often lead to financial support in the form of a Direct Payment or Personal Budget, although few of our respondents have any care funding.

The official guidance says: 'Assessment of eligibility for care services cannot be denied on the grounds of the person's IQ.' <http://www.autism.org.uk/working-with/autism-strategy/the-autism-strategy-an-overview/what-does-the-statutory-guidance-mean-for-me.aspx> but our respondents who were diagnosed with Asperger's syndrome as adults at the Learning Disability out-patient clinics or by mental health psychiatrists have told us that they were not offered the possibility of having one and nothing was mentioned about need or any follow-up appointments, unless the person had a low IQ or a clear mental health condition.

It was interesting that so many of our respondents did not know and still do not know what an SCA is – even those who are in receipt of statutory services, and as stated above, the majority of our respondents are not aware of their rights to request an assessment for social care, as provided by the Autism Act 2009, or to “expect” one after an adult diagnosis has been completed. Our concern is that there may be an assumption by clinicians that a diagnosis of Asperger's syndrome is not thought to be a social care issue, and that having Asperger's syndrome and mainstream ability means the person will most probably not have eligible needs when this may not be the case.

Another problem is the Autism Act 2009 itself that gives people with autism and Asperger's syndrome the rights to request an assessment of social care when few social work practitioners have autism specialism and the majority have minimal (one day's training) in the condition. It is common for those respondents who have had an SCA or a CPA, to find that once completed it does not address the condition of autism. One respondent had a recent SCA completed on two sides of A4 which she told us was based purely on her physical needs and she told us that her Asperger's syndrome was not being taken into account. Another respondent also mentioned that his SCA had not covered his Asperger's either. Even when an SCA is completed problems can still occur when social workers/care managers do not understand the condition. One individual told us that some care managers “have been poor. Meetings where I felt abused and not listened to and like a naughty child. It was horrible and led to a complaint.”

Findings and recommendations

Most of our respondents (see 1.7) told us that they are not aware of their rights, but when talking to them, they are also aware that the rights to social care may not give them the autism specific support that they require. Respondents told us that what they actually needed and benefitted from was autism specific support

and advocacy and pre-and post diagnostic autism specific mentoring; this was only currently available privately or through the voluntary sector. The funded local advocacy services were commissioned for people with co-morbid mental health problems or autism with a learning disability. None were specialists in Asperger's syndrome, or autism/Asperger's syndrome specific.

This finding reveals two important issues: people with autism/Asperger's syndrome in Shropshire are not aware of their legal rights to SCAs or CCAs; and psychiatrists, doctors and other health professionals are not offering SCAs to people who are diagnosed with Asperger's syndrome or even giving them information on the referral process. Another issue is that there is no statutory council or NHS funded autism specific service or advocacy support to be referred after diagnosis in Shropshire – only peer and social support from the voluntary sector or a private consultancy.

4.3 Access to funded support

7% of the respondents had received a Care Plan Approach (CPA) due to being under the care of Mental Health Team. It was a great concern just 4 of our respondents reported that they had personal budgets or care hours funded on their behalf and one is in the process seeking care funding, all 30 people interviewed faced similar issues, namely self-neglect, self-harm, autism spectrum issues, i.e. social communication, flexibility, understanding others, sensory problems, motivation etc, co-morbid health and mental health conditions and an inability to access healthcare alone or obtain sufficient advocacy. We also noted that 53% of our respondents stated that they are still either feeling suicidal or self-harming.

4.4 Conclusion

We have found in this survey that most of our respondents who are adults with autism/Asperger's syndrome in Shropshire are not aware of their legal right to healthcare and support, as legislated by the Autism Act 2009 and the Autism Strategy 2010. Even those with a recent adult diagnosis were unaware of their right to be assessed for statutory help.

There may be some reasons for this as many of our respondents hide or do not communicate their issues, as this survey has found. Many respondents may seem too intellectually able or independent to require additional support. It is also probable that professionals working with these individuals (GPs, psychiatrists or other relevant health workers) may be unaware of these rights – or are only referring those with more extreme and evident and more obviously eligible needs to those services. Whatever the reasons, our survey has found proof of a clear

unmet need and gap in health and social care provision for people with high ability autism/Asperger's syndrome in Shropshire.

FINAL RECOMMENDATIONS

We feel that due to the information we have gained from our Healthwatch Shropshire Funded Autonomy "Mind the Gap" Survey that service development should include:

- A wide ranging and compulsory well funded autism/Asperger's syndrome awareness training programme for all Shropshire Health and Social Care professionals. Also mandatory yearly refresher courses.
- The appointment of Autism Champions within these services.
- Greater accountability with regard to the needs of patients with autism/Asperger's syndrome in relation to dentistry, awareness of pain/ ill-health, self-neglect, suicide risk, self-harm and mental health issues.
- An annual health check (and dental check) for all people with a diagnosis of autism spectrum conditions including Asperger's syndrome and high ability autism with funded support provided if needed to attend it.
- A clear autism/Asperger's syndrome diagnostic pathway with easy to locate (online) initial referral contact details. One phone number for accessing the service, (not a switchboard number) which must be answered by a real person. A clear system to self-refer to the service.
- The diagnostic waiting times should be no more than 3 months. Autism/Asperger's syndrome specific mentoring support should be provided during this waiting period and after diagnosis. Peripatetic, professional, autism specific support should be funded for health and social care services including GP practices.
- Acknowledgment of high quality support already provided by Autonomy, STACS and NAS social/support groups. The creation of and funding for an autism specific professional and peer advocacy service for people with autism/Asperger's syndrome in Shropshire with a first point of contact that is accessible via email, text, Skype, face to face or by phone.
- Information on legal rights and a clear list of entitlements to statutory support with an expectation that these will be offered to those who are diagnosed and newly diagnosed with autism/Asperger's syndrome regardless of IQ. The provision of funded low level preventative social support for all individuals with high ability autism/Asperger's syndrome.

APPENDIX

WHAT IS ASPERGER'S SYNDROME?

Asperger's syndrome is a potentially hidden neurological condition which creates a different way of thinking which is both self-focused and intellectual. Autonomy calls Asperger's syndrome a "diffability."

As soon as we meet a person we make judgements about them, from their facial expression, tone of voice and body language we can usually tell whether they are happy, angry or sad and respond accordingly. People with Asperger's syndrome tend to find it harder to read the signals that most of us take for granted. This means they find it more difficult to communicate and interact with others which can lead to high levels of anxiety and confusion (<http://www.autism.org.uk>).

Asperger's syndrome is a lifelong condition that affects how a person makes sense of the world, processes information and relates to other people. Autism is often described as a 'spectrum disorder' because the condition affects people in many different ways and to varying degrees.

Asperger's syndrome gives rise to both gifts and impairments. With adequate support and guidance the autistic individual can apply his or her gifts to benefit society and enable financial independence. People with the condition tend to have difficulties in the areas of social communication, social interaction and social imagination because most 'normal' people find it difficult to accept people who are different.

With the right support and encouragement, people with Asperger's syndrome can lead full and independent lives.

A GP's Guide to Adults with Asperger's Syndrome

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Do you have patients who do not have serious mental health difficulties, yet find it hard to fit in socially? They may have an unusual social style, have few or no friends, experience anxiety or stress, and be unable to complete a college course or find stable employment. If so, they may have Asperger syndrome.

Not everyone with Asperger syndrome will have a diagnosis; in fact it's quite common for people with the condition to be diagnosed later in life. Many people will be unaware that they have a form of autism.

However, a diagnosis can be important because it helps people to make sense of the difficulties they may have experienced, understand themselves better, and access appropriate services and support.

In this guide, we have listed some questions you can ask a patient if they believe they have Asperger syndrome and wish to be assessed.

Autism spectrum disorders are described in both ICD-10 and DSM-IV international classification systems. If your patient list is 5,000, expect there to be between 18 and 24 people on it who have Asperger syndrome.

People with Asperger syndrome experience difficulty in communicating effectively with others. They often have problems making 'appropriate' conversation, and sometimes seem pedantic. They may have a poor understanding of non-verbal communication such as tone of voice, gestures and facial expressions. Some may find it difficult to make or maintain eye contact.

Many people with Asperger syndrome desire social contact but struggle to understand the reciprocal nature of 'typical' social interaction, and other people's language and humour. As a consequence, their attempts at interaction can sometimes seem rather awkward. It can make the person prone to teasing and isolation. Furthermore, their inability to read people's intentions can make them vulnerable and may mean they are taken advantage of.

People with Asperger syndrome often have a need for routines. Some may have intense, almost obsessive, interests. They may also rely heavily on other people in their day-to-day life in a way that you might not expect, given their apparent intelligence or independence.

Some people with Asperger syndrome can experience over- and under-sensitivity to sounds, touch, tastes, smells, lights or colours.

Be aware that adults with Asperger syndrome may have learned to cover up their problems, so signs of the condition will often be quite subtle. This is why people can experience difficulty in getting support.

As a result of difficulties with social interaction and communication, and a lack of support, many adults with Asperger syndrome are socially isolated and can consequently develop mental health problems.

Questions to consider when talking to adult patients who may have Asperger syndrome:

Does he or she:

- find many social situations, especially in groups, confusing (even though they may seem OK talking one-to-one with you)?
- often find it hard to guess what other people are thinking and feeling, or why they are laughing at a joke?
- find it difficult to make and maintain close friendships?
- have a history of problems at school or college, such as difficulties getting on with tutors or other students? Were they teased or bullied?
- find it difficult to secure satisfactory employment or stay in work?
- have any hobbies or interests which take up a lot of their time (or had these when they were younger)?
- get worried or annoyed about change, especially unexpected change?
- display difficulties with communication and appear to lack social intuition?

If the answer to most of these questions is yes, and your patient wishes to be assessed, it may be worthwhile discussing their case with the service that has responsibility for diagnosis. This is usually your local mental health or learning disability team.

Five reasons why diagnosis is important

- Autism, including Asperger syndrome, is a recognised disability. If someone meets the criteria set out in ICD-10 or DSM-IV4, they should have the opportunity to be diagnosed.
- Diagnosis can help a person to make sense of their history, which is often marked by difficult experiences and misunderstanding from others.
- Diagnosis can help a person to understand themselves better and make necessary adjustments for the future.
- Diagnosis can help families, friends, partners and carers to better understand and cope with a person's needs and behaviour.
- Diagnosis can help a person to access appropriate services. They may also be able to get support from their employer, college or university, social and housing services, benefits agencies and other organisations.

CASE STUDIES

Topic 1. Awareness of pain/ill-health (Section 3.2)

Reason: As mentioned in the report our members often have a high pain threshold and more than half of our respondents told us that they did not recognize when they are ill.

A. We asked the question “do you feel pain?”

Our respondents' comments and suggestions were:

- ❖ *“Only when it’s high amount.*
- ❖ *“I feel pain from things I shouldn’t and not from ones I should. I feel pain from burning if I burn myself – but several weeks later due to nerve damage. I don’t feel pain at the time of the burns and they are therefore very deep.*
- ❖ *“I use a scale of 1-10 and will mention it [pain] at 9.*
- ❖ *“I don’t register hurt much - slow processing*
- ❖ *“I have a low pain for teeth, it depends really as I can thump myself and not feel it much*
- ❖ *“Yes, but I block it out and then it registers that I have it and then I feel it. I am not aware if things are digging into me – i.e. tight clothes.*
- ❖ *“Yes, have a high pain threshold for certain things due to lifelong conditions.*
- ❖ *“I can cut myself and not know I’ve done it*
- ❖ *“My arms are not able to feel pain due to nerve damage.*
- ❖ *“It takes quite a while for me to feel it.*
- ❖ *“I did a test with putting a lit lighter against my skin and it does not hurt. But toothaches and headaches do. Small cuts on my fingers do hurt as well. But I had muscular pain and water on the knee and did not notice the pain and my carer saw it looked funny and went puffy. She told me to go to GP 10 days after it started.*
- ❖ *“I used to bump my head when working and then have to sit and recover – so yes a bit.*
- ❖ *“Yes, I have arthritis in my leg and it hurts.*
- ❖ *“She gets used to the slow build up – but did not know it hurt until it stopped hurting. Just accepted it.*
- ❖ *“When I self harm I like to see the blood and don’t feel pain. Takes quite a while for me to feel it. I can block out pain and get through it.*
- ❖ *“Often had operations cos caused [myself] so much damage in my muscles and nerves – my fingers get tingly sometimes.”*

B. We asked the question “do you know when you are feeling ill?”

Our respondents' comments and suggestions were:

- ❖ *“Mum has to tell me and mum notices and my attitude – I become more argumentative when I’m ill.*
- ❖ *“Yes I tell my carer now.*

- ❖ *"No, Mum tells me.*
- ❖ *"I know when I'm ill but not where or how I am feeling ill. I'm ok if I stubbed my toe but I struggle to identify where I will be ill.*
- ❖ *"Yes sometimes I can pinpoint what's wrong but sometimes I just feel ill – but I don't know why.*
- ❖ *"She will come down crying and then mum has to ask her*
- ❖ *People often tell me when don't look well. I will tell my boss I'm unwell.*
- ❖ *"50/50 – tummy upset ok but others tell me. My mum knew and recognised when I was ill.*
- ❖ *I don't take pain killers I forget to. Depends on severity. Sometimes I fight it. I don't like to take extra pills and meds.*

C. We asked the question "do you ask for help or advice when you feel ill?"

Our respondents' comments and suggestions were:

- ❖ *"Mum notices that I do not look well. I have to be bad to acknowledge I am ill. I will mention symptoms but not an illness as it might be due to other factors.*
- ❖ *"A long time ago I did not know but now I do know, as I've learned to feel it and work out what it is. I know what feeling sick is too.*
- ❖ *"Only when I'm really ill. I get on with it and ride it out. I had a high pain threshold for my operation, and take pills for period pain.*
- ❖ *"I will often be so obsessed about what I want to do that I put it off. I often don't know I'm ill till too late. I have to be reminded to use my inhaler as I am not aware when I am wheezing. I don't notice if I am too hot or too cold.*
- ❖ *"She copies mum as she does not ask for help.*
- ❖ *"No Mum tells me then I talk to the GP*
- ❖ *"Most of the time I recover from illness and feel I am a burden to people if asking for help*
- ❖ *"I try to sort it out myself by looking it up and trying to fix it as it takes a lot of effort to ask for help. I get pneumonia and UTIs regularly as I'm not aware when ill. I don't go to the loo often enough as it gets in the way.*
- ❖ *"Sometimes but not now as I used to be called a hypochondriac as I was ill so much, now they blame my mental health for it.*
- ❖ *"No – I sweat it out or work it out – once I asked my brother for help as I felt too ill and needed help to walk.*
- ❖ *"I was told not to go to the doctors unless it's severe. I used to go to work when ill. I have to be told to the doctor sometimes when ill – prompted. Got anaemia and still worked.*
- ❖ *"I get on with it and avoid doctors*
- ❖ *"Sometimes – then I get angry frustrated and go to bed or cut myself.*
- ❖ *"I can block out pain and get through it.*
- ❖ *"I will ignore it or go to the chemist. I deal with most flu and colds etc myself.*

- ❖ *"I get worried. I should have gone but did not mention things for 4 months. About something underneath but my carer prompted me."*

Topic 2. Accessing Primary Care Services (Sections 3.1/3.4/3.5)

We asked a range of questions about going to the GP surgery.

Our respondents had some comments and their suggestions are underlined:

A. Access to the surgery:

- ❖ *It would be really helpful to talk to one person and get advice. They need to press the right buttons on me rather than the other way round.*
- ❖ *I get worried about talking to strangers. I like the appointments to be on time. I don't like hanging around. I've waited for 40 minutes. I get irritable and have to walk around and look at magazines. I count the patterns on things.*
- ❖ *The surgery needs to have no children or babies running screaming and shouting so I will shout and scream and bang the door. Can't get away from the noise. Physically hurts me – like a pin sticking in my ears.*
- ❖ *It's ok; I get bored and fiddle with my phone. They call people's names and I can't hear them over the noise. I would like to have something visual to see what room to go to or a card with the info on as that would help. I've walked into the wrong room before now and got embarrassed. I also need a toilet nearby as I like to wash my hands a lot and I go to the loo a lot with anxiety when I'm waiting. It would be good if I could wait outside sometimes and be called in as I find it difficult sitting all the time.*

B. Talking to the GP:

- ❖ *"When Mum's there then she helps to keep me on track. On my own I forget to tell him what I need to tell him. I get a memory block and talk about wrong things. I even forget when he asks me if there is anything else he can do. He should just ask me what's the problem, and what can I help you with today. That would be helpful. I would then not get side tracked and go home without telling him and might not need my carer. I need to write it down too as that would help.do for me.*
- ❖ *"I always have my mum or a friend to help. I get confused and side tracked otherwise.*
- ❖ *"GPs don't listen to me and suggest me taking a pain killer but I would not be going there if I could take them for the pain. I have problems with hands and feet – all not working. I might become resistant to pain killers*

and I would not come to you if it was that easy! Want a scan of whole body, Get exhaustion in muscles when walking.

- ❖ *“He does not mince his words. I'm awful at describing things. Get confused. I know it's not right but can't explain...Always the same room, always sit in the same spot. GP comes and calls me.*
- ❖ *“I get worried about talking to them [GPs]. I get my carer to come with me most of the time but I've been twice on my own twice now. She knows I have autism so it's ok. They have to repeat what they say though.*
- ❖ *“No not believed much. I have to be ill to go there and to be shrugged off when I'm there and fobbed off is hard to deal with, it's easier if there is something physical as I can show it and ask what's wrong. I cannot say what pain I feel and where it is. Once I looked yellow and was exhausted and was asked where the pain was but I could not identify the pain in my abdomen.*
- ❖ *“Not initially and then I will start to participate - difficulties with expressing the problem. I use numbers as a pain or illness calculator – I will answer how are you? With I'm fine thanks as that's what I've been told to answer. They have to ask the right questions to get the right answer.*
- ❖ *“Some accents are difficult.*
- ❖ *“Have difficulty in explaining problems. I sometimes delay going, but eventually I tell them. Whether or not they actually seem to care is another question.*
- ❖ *“Some GPs do not seem sympathetic to anxiety or depression which can be linked to autism, do not have understanding or interest. This leaves appointments being wasted due to the attitude of the GP which sometimes borders on contempt. A feeling that the GP is judging what is important and what isn't, despite what the patient feels; giving the impression the patient is a nuisance and wasting their time.*
- ❖ *“I just don't bother. I just give up. He won't listen and I won't be believed.*
- ❖ *“I get nervous a bit – it's in my head what I wanted to say and get side tracked and then wish you had told them something else. I go in with a pain in my chest but start talking about my knees. What can I do for you today? When knee hurts more than chest. Can be a problem as I forget. Have stabbing pains in chest but not been able to tell the GP that...*
- ❖ *“Mum and Dad help me and then it's easy as they do the talking.*

- ❖ *"His responses did not make sense and he could not be challenged. I asked him for help with personal matter and he was unhelpful."*

C. GPs understanding of autism/Asperger's syndrome

We asked if the respondents felt that GP understands autism/Asperger's syndrome. These were our respondents' comments and their suggestions are underlined:

- ❖ *"I don't know but he is kind and helpful and had experience with mental health but not autism I don't think."*
- ❖ *"He understands me but I'm not sure he understands others. He has traits himself and in some ways I'm educating him as I'm not sure he has had training,"*
- ❖ *"One GP no but the other yes. I get the feeling she's been told about it but still does not know how to act with people on the spectrum. She asked me what is wrong ummmm and she was hard to talk to. Felt we'd been wasting her time. Got me down afterwards and depressed for rest of day. Made me iller than before."*
- ❖ *"No – tends to talk down to her and talks mostly to her carer. Knows she struggles with social and emotional. Respectful though. She will often walk out of the door saying that they are making assumptions about me – as she will play with toys and blood pressure stuff. Acting immature, but actually being inquisitive. She likes to fill a gap in her learning"*
- ❖ *"GPs have a lack of sympathy and a lack of understanding. They lack interest and feel no need to improve their understanding to benefit their patients. This applies to all bar one GP at the practice."*
- ❖ *She has not changed her approach since diagnosis. She is consistent though and is aware of my stress*
- ❖ *"Some don't – one did not believe me.... I'm not assertive. Majority don't. They did not suggest I had it. Accepted the letter from the specialist."*
- ❖ *"No none of them... Need to have one person at surgery that knows about autism – no one understands. I mention it and its dismissed. I knew I had AS and every time I asked they said social anxiety or depression. No one mentioned AS. They should have suggested it - the struggles I went through to get my diagnosis. Jumped thru hoops. Full training needed"*
- ❖ *"Now I've been diagnosed, yes, but not before."*

- ❖ *"He treats me for my mental health conditions really. That's all he does".*

Topic 3. Access to Dentistry (Section 3.11)

We asked our respondents about access to the dentist, these are some of their comments and suggestions:

- ❖ *"It's ok I'm ok with the dentist as I'm supported to go.*
- ❖ *"Have attended 1 appointment (last year) the first in 10 years. Could not find a dentist until last year. Have not encountered any dental problems in those years.*
- ❖ *"Did not go for 6 years as I could not afford to go and my dentist changed. Now attend specialist for SLD who are understanding and accommodating*
- ❖ *"My fillings are often falling out and I'm not motivated to get them sorted. They don't do a good job.*
- ❖ *"I don't have regular appointments anymore as I had not gone to some of them so they took my off the list. I brush my teeth well though.*
- ❖ *"Private, very thorough, never had any work done.*
- ❖ *"Not been since 17. My teeth don't hurt so I carry on. I went I needed emergency dentist but was refused so could not see one. I phoned and was abusive and I've not seen a dentist since January as now banned. I will try to get another one.*
- ❖ *"One time I did not go to the dentist for 11 years I do go now when they send me a letter. I did not like the dentist before as she did not understand, then I moved. I went off them. Then they did not send me appointments. I went to dentist and filled a form and then it got silly as I did not know what to do. I had to take antibiotics. I did not sign up to the dentist. I put it off. I did not see the new one for a year. I cancelled appointments. Then I had bad toothache and had to have hospital treatment and some teeth out 10 months later. My friend told me to go to the dentist.*
- ❖ *"I stopped going as he was lecturing me about cleaning my teeth and I argued with this. Now it's clear and straight will go. I know what I should do but struggle to do so. He has prescribed me toothpaste so more likely to use it. I'm brushing more regularly."*
- ❖ *I can't afford the fees. It's too expensive. I don't like drills and people feeling in my mouth due to sensory problems.*

Topic 4. Experiences of General Hospital (Section 3.13)

A. We asked our respondents about hospital treatment and this is what they told us:

- ❖ *"It was a bit of a shock. Was told it was all in my head and it was true but I had status epilepticus and then had a scan. Explained it but not the consequences of the procedure. Had treatment and then affected memory and words which /I had to look up. Was not told enough.*
- ❖ *"Hospital – did not like it. Helped me understand. Just did obs and drip but little else. Did not eat in hospital, food with ok. Brusque and not understanding, as I was in constant pain and they did not give me pain relief for three days until the last day Not allowed my mood stabiliser. Not sleep – not for 36 hours. Shock and elderly lady talking too much. Not allowed my proper meds. Got very upset and low and got MH staff down – RAID team were helpful. Arranged discharge and crisis team to see.*
- ❖ *"They were not particularly helpful but not hostile. Lots of waiting in hospital though and that gets me agitated. I've left hosp early without signing out cos staff too busy.*
- ❖ *"Not like being in hosp with others. Overwhelming and scary one your own but in amongst others and no one listens to you except the chaplain. who did not judge – he was a kind of key worker! Routine looking out the window. Can't choose what you do. Much happier in private room.*
- ❖ *"They found me frustrating but it took me ages to work this out..... I did not really get that they had lots of other patients to see and care for.*
- ❖ *"I had back pain and they talked too fast. I did not understand most of what they said and just sat and smiled."*

B We asked what would have helped to make your hospital visit better and these were some of our respondents' comments/suggestions:

- ❖ *"More medically competent staff!*
- ❖ *"Yes – but training needed with MRI scan as I was claustrophobic and I got stressed and should have had more reassurance. Hospital is one of my special interests so I love going there and learning about what happens there.*
- ❖ *"Might have had a different approach if I had been diagnosed. Not understand MH. Visiting hours a problem. Not had visitors come. Rubbed it in.*

- ❖ *"I have regular out patient appointments for my physical condition and understand why they are needed. There are sometimes issues because they do not understand Asperger's/autism which leads to confusion. On one occasion I went to A&E and tried to get out of the hospital through the main building and security guards chased me and were aggressive. I am now frightened every time I return to the hospital.*
- ❖ *"One time I was in hospital for several days and they were too busy and I could not get their attention. I have mobility problems and needed support so had to phone my friend to ask if she could phone the ward to ask them to help me to the toilet!*
- ❖ *"Training needed, often misjudged. With the security guards the situation was an over-reaction from them, the aggression was not needed and they tried to manhandle me.*
- ❖ *"I find noises are more painful than cutting and burning and I have to cover my ears.*

Topic 5. Experiences of Psychiatric Hospital Care (Section 2.3)

3 of our respondents told us of their recent experience of mental health hospitals, and 1 avoided being sectioned by "running off!" Here are their comments/ stories:

Respondent "A":

"Was in Redwoods – Oct – March. Sectioned. Got worse in hospital and tried to kill myself in hospital – worked out check intervals – asked for constant but this was stopped. Ligatured and cleaners found me and put in solitary after that. A nurse told me and threatened me if I did not calm down. I had alcohol and all meds lorazepam – was attacked by another patient.

"Did not fit and had to be with others more ill than I was. A really weird environment. They don't listen to me.....

"I needed to go out and have a walk and kept trying to go out to get away but they did not trust me and so I would escape and sneak out and then be away all night and then the police were called. I got told off and even sent a police helicopter out and they got cross. I used to send Google maps images to them as to my location.

If I did not eat I was not helped – I was not allowed to eat in my room. I had to eat in the dining room with others. I was told off when I did not eat or just left. No consistency. I don't like eating around people especially those I did not know.

"I would ask the nurse for someone to talk to and they would say yea and then no one would turn up. I could only get attention and have someone to talk to it I did

something wrong. It made me worse. Before I went in I did only superficial cutting but in hospital I cut much deeper as my light cutting was shrugged off as not enough. Comments like I've seen worse. I learned to burn myself too with lighters as they are easier to get hold of than knives. Sharpener blades were smuggled in – sneaked off and bought paracetamol and then took them.

“.....I was accused of dressing inappropriately too as I had shorts on. I can't stand the heat. I am hyper sensitive to heat and sound. Buzzers went off when things go wrong – kept ringing in my head for hours afterwards. Had noise cancelling headphones to block out the noise.

I'm good at acting so I pretended to be ok to get well to get out.”

Respondent “B”:

“Not good as I actually got worse in hospital – they did not have time to talk to me and I ended up trying to kill myself from frustration as they were too busy and thought I was a nuisance. I ligatured myself.

Did the staff understand autism/ Asperger's syndrome? *“They only thought it was PD not Asperger's so did not help with my Asperger's.*

What would have helped to make your hospital stay better? Explain below:

“Talking to me, listening to me, understanding Asperger's, I was bored, I used to wait for my food and sleep. Used to read magazines and go out every half hour for a cigarette and meet and chat to the other patients. Having a smoke was better therapy than being in the ward.

“It was worse at secure until they let me go out. One nurse told me “I wish you would not self harm as it hurts me to see you do that” I have Asperger's – it made me want to self harm more! I nearly died by trying to kill myself.

“My care was too medicalised – too mental health. Not supportive. Nurse based.”

Respondent “C”:

She told us that she had been offered an advocate, but having ASD she did not know what an advocate was so turned one down, when this service would have very much helped her during her 6 month hospital stay. Although well cared for she told us of psychiatrists “avoiding” her and making excuses not to see her when they knew she had autism. She also had problems with hospital food as she was so hungry having not eaten her meals and had to often go out to get chips.

Terminology and Abbreviations

ADHD	Attention Deficit Hypersensitivity Disorder
ASD	Autism Spectrum Disorder
ASC	Autism Spectrum Condition
A S	Asperger's Syndrome
CCG	Clinical Commissioning Group
IQ	Intelligence Quotient
GBLT	Gay, Bi-sexual, Lesbian and Transgender
VLDAS	Very Late Diagnosis of Asperger's Syndrome
OCD	Obsessive Compulsive Disorder
LD	Learning Disability
MH	Mental Health
SCA	Social Care Assessment
CCA	Community Care Assessment
CPA	Care Plan Approach
CBT	Cognitive Behavioural Therapy
DBT	Dialectical Behaviour Therapy
A&E	Accident and Emergency Department
NAS	National Autistic Society
STACS	Shropshire and Telford Carers' Support

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OTHER PUBLICATIONS BY SARA HEATH & PHILIP WYLIE

2013 UK Survey about Very Late Diagnosis of ASD

By Philip Wylie and Sara Heath (2013)

If you wish to download this survey the report is:

<http://www.shropshireautonomy.am55.co.uk/sites/45/survey-report/late-diagnosis-survey-v7.pdf>

Very Late Diagnosis of Asperger's Syndrome: How Getting a Diagnosis can Change your Life

By Philip Wylie with forewords by Sara Heath and Luke Beardon

Published by Jessica Kingsley Publishers (2014)

This publication is available for sale at Autonomy Shropshire or via the publishers: <http://www.jkp.com/catalogue/book/9781849054331> and is partially based on the late diagnosis survey of Autonomy members.

Further information about this book is available at: www.latediagnosis-aspergers.pw and www.facebook.com/JKPAutism/

The Nine Degrees of Autism: A New Developmental Model for the Reconciliation and Alignment of Autism and other Hidden Neurological Conditions

By Philip Wylie et al. with significant contribution by Sara Heath and other leading autism experts including Temple Grandin, Wenn Lawson, Luke Beardon, Stephen Shore, Tony Attwood, Manuel Casanova, Louise Page, Michael Fitzgerald, Debra Moore and Altazar Rossiter.

Publication date TBC (2015) Routledge

Further information: www.ninedegrees.pw or www.phil.asia

Services provided by AutonomyPlus

Autonomy and AutonomyPlus provide the following services:

- Free membership
- Regular bi-weekly social groups for adults who are on the spectrum
- Social gatherings, activities, outings and events for members
- Mentoring and coaching
- Advocacy and 'translator' for health and social care professionals, employers, education providers etc
- Pre-diagnostic assessments for adults who wish to explore if they have an autism spectrum condition
- Autism consulting and training for healthcare professionals and doctors
- Support with benefits and social care advocacy

Autonomy has public liability insurance and a 'safeguarding adults at risk' policy. Moreover, Autonomy protects its members by having undertaken Disclosure and Barring Service checks of volunteers.

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