

“MIND THE GAP” Summary

**A Report on Health and Social Care Access Issues for Adults
with Asperger’s Syndrome and High Ability Autism in
Shropshire**



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Supported by Healthwatch Shropshire Research Grant Funding



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MIND THE GAP: SUMMARY REPORT ON HEALTH & SOCIAL CARE ACCESS ISSUES IN SHROPSHIRE

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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 Autonomy, Dr Danny Beath and Michael Harvey

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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 are identified in healthcare provision we have stated our respondents' comments and suggestions for improving services.

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.

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.

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.