

Meeting between Department of Health representatives, people on the Autism Spectrum, their carers and representative organisations. February 19th 2.00pm

Michael Swaffield	Autism Policy Lead - Department of Health
Anya Ustaszewki	Self-advocate member of the Autism Programme Board
Sue Smith	Principal Health Lead for the SEQOL service in Swindon
Dr Ian Ensum	Consultant Psychologist, Bristol Autism Spectrum Service
Cllr Chris Chappell	Advocate for people with Learning Disabilities
Michelle Baillon	Parent
Helen Bouchen	Person on the Autistic Spectrum
Colin Bouchen	Parent
Ben Clayton	Person on the Autistic Spectrum
Jane Clayton	Parent
Richard Green	Parent
Catherine McGowan	Parent
Valerie Fitch	Hereford Carers Support, Person on the Autistic Spectrum and Parent
Sue Black	Hereford Carers Support
Sylvia Nicholls	Chair Hereford Disability United (HDU)
Mandy Shrimpton	National Autistic Society – Hereford and Worcestershire branch
Sara Siloko	Hereford Disability United
Colin Javens	Herefordshire Health Watch
Aubrey Baillie	Independent consultant psychologist in Autism
Laura Simmonds	Student
Sean Slater	Head of Learning Disability Psychology, 2gether NHS Trust
John Gorman	Commissioning Support Officer, Adult Social Care
Bob Parker	Interim Head of Adult Safeguarding, Adult Social Care
Apologies	
James Baker	Person on the Autistic Spectrum
Mary Godwin	Parent
Paula Daniels Simmonds	Parent
David Malins	Herefordshire ASPIE
Jonathon Williams	Herefordshire ASPIE
Rose Hunt	Herefordshire Mencap
Carol Soble	Specialist Teacher for Complex Communication Difficulties
Helen Webb	Altogether Trust
Mark Hemming	Locality Director of 2gether's services in Herefordshire

The purpose of this meeting was to discuss the draft changes already proposed for the revised national autism strategy due to be published in April, to obtain views on autism provision locally and to gather ideas and themes for the revised strategy.

The main themes and topics discussed included;

Raising Awareness

Including;

- The lack of awareness of what autism is

- The lack of training to raise awareness of autism
- The lack of understanding amongst professionals of what autism is.

Identification of those on the spectrum

- Aids to help those on the spectrum to be identified in everyday life can be a help.
- Identity cards – these are available currently. Could new versions be photo cards to prevent fraud?
- ‘Medi-care’ style jewellery can be used to help identification
- An Autism “passport” is an idea that is being considered
- However any such aid to identification relies on people (Police, duty solicitors, A&E Staff and other professionals) understanding the condition and what it means
- All awareness training needs to be tailored to the specific profession and circumstance that someone on the spectrum is likely to be encountered in.
- It was acknowledged that money and funding would always be an issue when raising awareness

Conference

Cllr Chappell announced that he would be chairing a conference in May that will be run to get the views of as wide a body of people as possible on how a reconstituted Learning Disability Board would operate. He was keen to point out that people on the autism spectrum, whilst not specifically having a learning disability, would be welcome to attend and participate in the work of the new Board. It was noted that around 40% of people on the spectrum also have learning disabilities.

Sue Smith from Swindon said that they had done something similar and that it had been very successful.

Sylvia Nicholls said that Hereford Disability United had run a successful autism seminar in November and that another was planned for June 25th at the Hinton Community Centre.

Getting the views of those on the spectrum

- It was asked whether there are reliable figures on the number of people in the county on the spectrum.
- There is not currently a complete register of all adults on the spectrum although new reporting arrangements due later this year will make recording of people easier. There are more complete figures on children on the spectrum.
- Sue Smith from Swindon agreed that getting accurate figures can be difficult. An overall estimate of 1:89 of the general population is a realistic figure but getting a hard figure of how many of these people need help is more problematic. GPs could be encouraged to record more data although this might have a cost.
- Methods of collecting views could include IT, internet, local groups, the Hereford Times, and so on.

It was agreed that these ideas will need to be worked on further

People on the spectrum with a high IQ

- These people often do not get any help. Late diagnosis is often an issue and a lack of awareness within social services can be a problem.
- Diagnosis of autism does not automatically lead to financial help. This needs to be understood and we need to be honest with people, families and carers that this is the case. What is needed in these instances is more well directed, appropriate low level help.

Joint working and co-operation

- Better training and cross agency co-operation are key. An understanding that finances are tight and that the council is not always the only source of funding is also important.
- Joint working is an opportunity to share funding and expertise, especially in bid writing.

- Joint working is not about finding large amounts of new money – it is about making the most of what funding we have. If everyone were to contribute to the funding pot this would help.
- There is also a need for better co-operation in matters to do with eligibility. Person centered planning is needed to ensure that those people on the spectrum – especially where they also have other conditions– can get help for needs associated with their autism.

Crisis funding

- It was agreed that this is an important area. The group wondered how someone not known to the authorities would get crisis funding when it was needed.
- Michael Swaffield said that crisis funding and preventative funding are very important aspects that need to be considered.

The view of those on the spectrum

- Michael Swaffield asked those at the meeting who were on the spectrum, what help they feel they need.
- It was agreed that autism awareness amongst job centre staff needs to be improved. Staff members are not sympathetic. Some help with seeking employment is available through charities such as the Shaw Trust but often employers are wary of employing someone on the spectrum.
- Work in charity shops can be seen as a way of gaining experience. Job getting agencies should link to the charity shop sector to see if more could be done.
- It was agreed that employers need to have greater awareness of autism. Sue Smith said that in Swindon they have used Mindful Employers to help those with mental health issues. Could something like this be used here for those on the spectrum?
- Sue Black asked if there were ‘big sticks’ available to combat or prevent discrimination. Michael Swaffield said that there is the threat of legal challenge but these do not always work as not all instances of discrimination are clear cut. It would be better if everyone worked together as better links and better relationships lead to simpler solutions. A strong Partnership Board is a good way forward

Getting funding through bids

This can be difficult as government agencies appear to favour larger national bidders over smaller local ones. EU procurement rules can also work against smaller local groups as the threshold at which bids must be widely advertised can be quite low.

Question – could grants be used as a funding vehicle rather than contracts?

Action – Bob Parker and John Gorman to investigate further

FACs and eligibility for assistance

- It was asked what help is available for people on the spectrum and their carers.
- There is no separate pot of money. People on the spectrum are assessed in the same way as everyone else using the FACs criteria which in Herefordshire are set at ‘critical’ and ‘substantial’ (the two highest ratings). If assessed as eligible the applicant would be able to get help. This help might include a Personal Budget.
- There is an issue about those people on the spectrum with an average or higher IQ, or who are not diagnosed, or who are cared for within a family environment – these people’s needs would be unlikely to qualify them for help.
- There is also a requirement for an applicant to have a social worker in order to progress an application for help. Experience from around the table showed that it can take some considerable time to get a social worker and for an application to even get started. The application process can also be cumbersome and the smallest change in requirements can cause applications to go back to the start time and time again.

- Bob Parker agreed that change was needed to improve services and acknowledged that there is money 'locked up' within the workings of many different statutory bodies such as the council, health, DWP and others. Looking at how these organisations can work together more efficiently, with less duplication of effort, may free up money that might then be available to help people on the spectrum.
- The system of 'Panels' to assess need and entitlement is also fraught with difficulties. It was agreed that this system needs to be looked at and reformed. Bob Parker informed the meeting that a large body of work was currently underway to look at the entire assessment process and that changes to make it more fit for purpose are being considered. This work will take time but changes will be made.
- It was agreed that the staff members who carry out the assessments need to have a greater awareness of autism and how it affects people and what help is needed to be able to live a better life.
- A further issue is that of equipment and how to get hold of it. This too can be a drawn out process.
- Person centered assessments were discussed and it was felt that this could make changes for the better. Prevention is also an area that should be looked at as this would help more people on the Autism Spectrum at the lower end of FACs eligibility as well as those who are not currently eligible.
- It was agreed that FACs and the Autism Act are not a good fit. Michael Swaffield informed the meeting that he was currently in negotiations to see if funding could be found to fund pilots to look at how time limited help could be implemented – especially in time of crisis – without having to be so bound to the FACs process. His Department is currently looking at different models.

Other discussion points

There should be an autism champion in each GP's surgery and in every job centre.
Student doctors are also a useful group to target with awareness training

Sylvia Nicholls informed the group that she was investigating the setting up of a virtual job club. It was suggested that a one stop shop for advice and guidance would work. This could be on a coffee shop model. This could also be a signposting service – Mandy Shrimpton said that she was setting such a service up and that she needed volunteers to make it happen.

Summary

Michael Swaffield then brought the meeting to a close by thanking everyone for attending and for their contributions. He felt that the key points he had heard included;

- The enthusiasm to help to make changes needs to be coordinated
- Autism needs to be on all agendas
- There is a need for better and more efficient systems

He reminded everyone that the current, and the refreshed strategies, are about allowing people on the spectrum to fulfill their potential