

**Autism Partnership Group – inaugural meeting
Feb 13 10am Room 22a Brockington**

Present

James Baker	Hereford Make CIC and Person on the Autistic Spectrum
Helen Bouchen	Person on the Autistic Spectrum
Valerie Fitch	Hereford Carers Support, Person on the Autistic Spectrum and Parent
Michelle Baillon	Parent
Colin Bouchen	Parent
Jane Clayton	Parent
Paula Daniels Simmonds	Parent
Mary Godwin	Parent
Catherine McGowan	Parent
Sue Black	Hereford Carers Support
Rose Hunt	Herefordshire Mencap
Sylvia Nicholls	Chair Hereford Disability United (HDU)
Jonathon Williams	Herefordshire ASPIE
Mandy Shrimpton	National Autistic Society – Hereford and Worcestershire branch
Aubrey Baillie	Independent consultant psychologist in Autism
Cllr Chris Chappell	Advocate for people with Learning Disabilities
Les Knight	Head of Provider Services – Children’s Well Being - Additional Needs
Sue Little	CCG – representing Lynne Renton
Sue Riley	Herefordshire Council Children with Disabilities
Cathy Meaney	Advanced Healthy Lifestyle Trainer - Public Health
Carol Soble	Specialist Teacher for Complex Communication Difficulties
Helen Webb	Altogether Trust representing Sean Slater
Richard Gabb	Assistant Director, Commissioning, Adults' Well-Being & Independent Living
John Gorman	Commissioning Support Officer
Bob Parker	Interim Head of Adult Safeguarding

General points

It was agreed that the name of this group would be the Autism Partnership Group (not ‘Steering group’ as shown on the agenda).

It was agreed that the accepted term of reference would be ‘Person (or people) on the Autism Spectrum’

It was agreed that in future the meeting arrangements for this group should consider accessibility, disabilities such as hard of hearing and a more central location. Other media such as Skype and phone conferencing should also be considered. Aubrey

Baillie mentioned Second Life.com which can be used as suitable conferencing facility for people on the Autism Spectrum.

Bob Parker noted that the Autism Partnership Group (APG) was not a sub group of the Learning Disability Partner Board (LDBP). The work of the APG will cover a wider spectrum than learning disabilities and although it will cross reference to the LDPB it will be distinct from it (see also, later discussion on arrangement to chair future meetings)

Sylvia Nicholls told the meeting that HDU had held a seminar on autism in November and that report on the outcomes had been produced. It was agreed that this report would accompany the minutes of this meeting.

ACTION – HDU report to be circulated to attendees with the minutes

Cllr Chappell introduced himself as a newly appointed ‘Champion or advocate for people with disabilities’ and asked for the group to contact him with examples of good practice, ideas, issues etc.

He can be contacted at cchappell@herefordshire.gov.uk

Bob Parker suggested that the meeting should depart from the published agenda and that it take the draft Terms of Reference later in order to listen to the experiences of attendees. This was agreed.

Bob asked for those around the table who were a person on the autism spectrum or parents or carers to say a few words about their experiences. This was very powerful, and provided a ‘lived experience’ for the meeting attendees.

The typical themes emerging from people’s experiences included;

- There is a need for some basic help with having a social life and caring for oneself
- We cannot access help without a Social Worker
- It is difficult to get support to obtain, and maintain, employment. Advice from Job centres is poor. • Those on the spectrum often set up their own businesses in order to get work
- No local support groups for people on the autism spectrum – the nearest are Gloucester or Worcester
- Not easy to get a statement or a diagnosis. Often assessment can take too long.
- Help can sometimes be removed - which is not helpful.
- People on the autism spectrum do not easily fit into categories and so often fall between services
- Services need to treat the whole person not just a label
- Not enough respite available and what is available is not always suitable
- Professionals such as Teachers and the Police can ‘get it wrong’ with people on the autism spectrum as they ask the wrong questions or do not understand the problems.
- There are other tests of IQ (other than just academic) that should be used when assessing eligibility for help – such as ‘functioning IQ’ and ‘social IQ’.
- Following NICE guidance on assessments would be helpful
- We need to look outwards to others for best practice

- For other recognised disabilities 'reasonable adjustments' would be made to help with employment and social interactions - these are also needed for people on the autism spectrum
- Staff shortages together with a lack of finance often mean that therapeutic services have not been available.

Val Fitch recommended that members of the group access the National Autistic Society website for help and advice – see <http://www.autism.org.uk/>
 Sylvia Nicholls noted that there is also a useful newsletter for teenagers on the site.

Terms of reference (TOR)

The group discussed how often it should meet and whether it should be co-chaired by the Council and a person on the Autism Spectrum.

ACTION - Views on the frequency of meetings and who should chair meetings to be fed back to John Gorman

Sue Black asked for clarity as to where this group sits in the governance structure and who it reports to. Bob Parker agreed that governance should be set out better in the TOR and said that he would look into it.

ACTION – Bob Parker to draft governance arrangements for the group to be included in the TOR

Sylvia asked whether the name of the group should 'action' rather than 'partnership' Bob Parker agreed to consider this

ACTION – Bob Parker to consider name change for group

Les Knight said that the TOR needs to reflect governance for children's services. **This was agreed**

He also pointed out that the name for Childrens Services had changed to Childrens Well Being and that this should be reflected in the TOR. **Agreed**

ACTION – The draft TOR to be e-mailed to members with the minutes

ACTION – The group were asked to feed any comments on the TOR to John Gorman

ACTION – References in the TOR to be changed to 'People on the autism spectrum'

Group Membership

Bob Parker said that this will be a voluntary, non-fee paying group open to all those interested in Autism. The group is not a formal body. It was acknowledged that the size of the group would change over time and that new people and bodies would be asked to attend and join as the need arose.

Childrens Wellbeing:

Les Knight then spoke to the meeting about the range and type of services available in Herefordshire for children on the autism spectrum

These include;

- Diagnosis; there is a group (which includes Carol Soble) that has been trained to use the ADOS diagnostic tool. This has helped improve the quality of diagnosis in children.

- A diagnostic pathway for children has been agreed (though not published) – this would form part of the Local Offer*

**The local offer provides information on what services children, young people and their families can expect from a range of local agencies, including education, health and social care. Knowing what is out there gives you more choice and therefore more control over what support is right for your child. The offer provides information on a number of things, including:*

special educational provision; health provision; social care provision; other educational provision;

training provision; travel arrangements for children and young people to schools, colleges and early years education; and preparing for adulthood, including housing, employment and leisure opportunities.

- Children aged over 10 years of age are dealt with through the CAMHs services and Dr Sabah Jaafar has been working with children as young as two years of age to diagnose autism.

- Les noted that a diagnosis does not always lead to a statement and that funding for help was separate to the existence of a statement. Statements are due to disappear to be replaced with an “Education Health and Care Plan”. This is currently being worked on.

- Les noted that there is a service for training children – and adults – on independent travel. Contact is Dave Magness at dmagness@herefordshire.gov.uk

- Carol Soble carries out autism awareness training for teachers. Valerie Fitch asked if volunteer people on the Autism Spectrum could also attend these sessions to help with the training. Carol agreed that this could be done. Val said that Worcester College has a course for social workers which includes input from people on the autism spectrum to heighten awareness.

- Respite – Les noted that a recent re-commissioning exercise had not produced the expected outcomes and that the shape and design of the service was again being reconsidered.

Universal services – (such as sports clubs) – **Les said that he would welcome ideas on how these might be made more inclusive for all users.**

- Bullying – Les noted that Joy Burnet is the Council’s officer with a remit to deal with bullying – her e-mail is joy.burnet@herefordshire.gov.uk

- Employment – Les said there is an 18 to 25 steering group and wondered whether the autism partnership group would wish to have an advisory role on this group to ensure that the needs of those on the autism spectrum were taken into account.

It was agreed that this would be a good idea.

Les noted that Jobcentre Plus are on the 18 to 25 steering group and that the autistic partnership group should perhaps speak to their rep, Mike Dzioba, to see how autism awareness could be improved within jobcentre staff.

In summary, Les said that a Local Offer was being worked up in which all services would be included and it would be published in an accessible format. This would be available from September.

ACTION – Les to supply John Gorman with contact details for the local offer.

Sylvia Nicholls said that she was investigating setting up a 'Virtual World Job Club' in which 'players' would learn about social skills, job hunting skills and life skills. This would require around £4K of funding and she said that she would look into obtaining funding.

Group membership

Bob Parker asked whether the Police should be invited to future meetings. **It was agreed that they would be.**

Aubrey Baillie noted that a West Mercia Police contact that might be useful was Ann Shaw.

In addition it was agreed that the council's cohesion team should also be invited.

ACTION John Gorman to note for future meetings

The Strategy

Bob Parker took the group through the high level priorities within the local Autism Strategy – these are;

- Increasing awareness and understanding for those who provide services to people with ASD
- Improved identification and diagnosis of ASD in children and adults, leading to assessment of needs for relevant services
- Improved transition planning in relation to the provision of services to people with ASD as they move from being children to adults
- Local planning and leadership in relation to the provision of services for adults and children with ASD
- Support for parents, families and carers
- Appropriate support for people with ASD in the criminal justice system
- Getting the right housing and housing related support for those with ASD
- Helping people with ASD into employment, training and Further Education

He said that there was also an action plan that will need to be reviewed and strengthened.

ACTION – draft action plan to be circulated to the group

ACTION - At the next meeting an update of progress would be given to the group

It was also noted that the strategy had been to the Council's Leaders Briefing, the Health and Well Being Board and that it would shortly go to the Clinical Commissioning Group

ACTION - Bob Parker agreed to confirm when it is ready to go into the public domain

Other issues discussed

Sue Black said that a key issue is that of accessing services. She asked if this group could influence provision of services such as Housing. Richard Gabb said that it was for this group to help assess need and to make submissions to the council on the shape of future commissioning plans for things such as this.

Sue Black also said that work was needed to improve services such as Home Point. Richard Gabb said that new eligibility policies were being introduced and the roll of this group would be to influence and lobby interested parties.

Any other business:

Jane Claydon noted that the NAS had published a piece on the launch of this group on their website – see <http://pushforaction.blogspot.co.uk/2014/02/a-new-autism-agenda-in-herefordshire.html>

Bob Parker recommended the Autism Bedfordshire website as a useful source of information – see <http://www.autismbedfordshire.net/>

Mandy Shrimpton said that she was setting up a signposting service through the local NAS branch and that she needs volunteers to help set it up and run it. For more on the local branch see <http://nasworcsandherefordshire.webeden.co.uk/#>
Mandy also runs the Rainbow Autism group – for further information contact them at information.autism13@gmail.com or call on 01684 312760

Bob Parker took the group through the upcoming visits by the Department Health. These are on February 19th and members of the group can attend the 2pm session. A document has been circulated – further copies can be obtained from John Gorman

Sylvia Nicholls said that the next HDU Autism seminar would be June 25th at the Hinton Community Centre.

James Baker asked whether expenses would be paid for members of the group.

ACTION – Bob Parker said he would look into this

Date of next meeting –

To be decided for a date in May 2014.

Venue to be decided

It was agreed that the Police would be invited to the next meeting to present on hate crime and that the NHS, Together NHS Foundation Trust and the Adult Social Care Team would be asked to future meetings