

Autism Partnership Board Meeting 30/10/18
10am-1pm Committee Room, Town Hall, Hereford
Attendees

Mary Simpson	Healthwatch
Silvia Nicholls	Hereford Disability United
Paula Daniel Symonds	Parent Carer
Gill Gorle	ACSYL
Rob Gorle	ACSYL
Debbie Hobbs	Hereford NAS
Rhiannon Mainwaring	Lead Nurse / Wye Valley NHS trust
Aubrey Baillie	Autism Advocate
John Gorman	Herefordshire Council
Paul Choppen	Herefordshire Council
Laura Ferguson	Herefordshire Council

Apologies

Valerie Fitch	Parent / someone on Autistic Spectrum
John Burgess	CCG
Jade Brooks	CCG
Amanda Bell	Priory Care
Sharon Mayglothling	St Michaels Hospice
Les Knight	Herefordshire Council
Lisa Masters	Occupational Therapist

John welcomed everyone and then asked everyone to introduce themselves.

Better Standards of Care - Rhiannon Mainwaring

Rhiannon introduced herself as the lead nurse at Wye Valley NHS trust since 2016. Rhiannon explained that NHS Improvement has worked with people who use health services and their families, and health services colleagues, to develop 4 standards that NHS trusts should meet. Rhiannon has been working on making sure these standards are implemented in Wye Valley NHS trust.

The 4 standards are:

1 - Protecting and respecting the rights of people with learning disabilities or autism. Rhiannon explained that this involves ensuring the individual's human rights are upheld, as well as listening to the individual and their family/ carer. Onside advocacy and Independent Mental Capacity Advocates are an organisation that the NSH use to facilitate this.

2 - Involving people and listening to people. This involves making reasonable adjustments from pre-op onwards using the care pathway and Hospital passports. In February 2018 the SACI group was set up. The group supports people with dementia, learning disabilities and autism who have communication impairments. The group have made sure resource boxes are available to patients. The resource box includes communication aids. Also the Dementia champion at the hospital set up the Living with Dementia group which has been running for 3 years.

3 - Making sure NHS trusts have the right staff with the right training – Rhiannon said staff are trained to understand how to support patients with dementia, learning disabilities, autism and delirium. Debbie Hobbs mentioned that on the 23 October 2018 in a debate in Parliament the minister for Care, Caroline Dinenage had agreed to include Autism in plans for mandatory training for healthcare staff.

A Discussion took place about ways to make stays in hospital more comfortable for patients with Autism. Debbie Hobbs suggested using social stories to explain information about the patients hospital stay to them in advance.

Action-Rhiannon Mainwaring to liaise with Debbie Hobbs.

4 - Special health services for people with learning disabilities - this only concerns specialist learning units, not universal services such as the hospital.

Rhiannon mentioned that Wye Valley Trust was in the process of moving to paperless electronic patient records (EPR). She noted that numbers were currently low as it was proving difficult to get reliable data.

Rhiannon said she wanted to use the Autism Partnership to access experts by experience. If anyone would like to get in contact, her email is: Rhiannon.Mainwaring@wvt.nhs.uk.

Self-Assessment - John Gorman

John Gorman explained that every 18 months Public Health England asks local authorities to complete a Self-Assessment with help from their partners to help gauge progress in implementing the Autism Act. The Self-Assessment comprises of 129 questions covering areas such as: Governance, Training, Housing, Care Pathway, Transitions, Planning, Police and Legal services and Employment.

John explained that we have improved in 3 areas but that a key area that needs addressing is to elect an independent chair to the group. Generally though it seems that findings will be similar to last time. It was noted that the self-assessment does not measure intent, but actual's that can be easily measured. John will send out the Self-assessment Framework tomorrow 31 October for comment.

Action-John to send out the Self-Assessment Framework to the group. Comments to be returned by November 9.

Autism Strategy – Laura Ferguson

Laura informed the meeting that the strategy had been signed off by the Cabinet on 18 October. CCG are still to formally sign the document off, but it has been adopted by the Joint commissioning board (JCB)

Action – Laura to circulate the agreed strategy document.

The strategy has the full support of the Cabinet. At a pre meeting (Called the Leader's Briefing) the Leader had asked for a budget to be identified to help implement the strategy. A bid has been prepared for £70k to help with awareness training, which can be scaled down depending on available budget. This bid is still to be agreed.

There will also be joint Autism and Learning Disability Champions. These roles will be taken on by Cllr Rone and Cllr Swinglehurst.

The implementation plan – Laura noted that there were five areas that were owned by the Board. These are;

- 1 - Setting out an awareness raising plan for the coming year – Debbie suggested structuring this around the NAS national autism week starting on April 2 2019.
- 2 - Scope the work needed to improve health services for people with autism
- 3 - Construct good practice guidelines on housing and buildings
- 4 - Construct good practice guidelines on working practices. Debbie said that the NAS already has some guidelines that could be used as a basis for this work.
- 5 – Awareness training for councillors.

The meeting then discussed how the board might influence and drive the delivery of the autism strategy.

It was agreed that key delivery partners would be identified and that they would be asked to produce a report to the Board covering progress, issues, successes and problems. These reports would be circulated to board members in good time to allow them to read and understand the reports. The partners would then be asked to attend a board meeting to discuss the reports and answer questions from the board.

It was agreed that future meetings would follow a general pattern of;

- First hour – report, Q&A one
- Second hour – report, Q&A two
- Remainder of meeting – review of the strategy implementation plan plus AOB.

The key partners identified to be included in this process were;

- The CCG
- Public Health
- Education / Adult Learning
- Health services including the NHS
- Employment services

Other partners will be identified as needed.

The role of the Autism champions was then discussed. It was agreed that one or both would be invited to the next meeting. It was also agreed that they would be asked to take on the role of Chair of the Board.

Action Laura Ferguson to invite Cllrs Rone and / or Swinglehurst to meeting in January.

Action- create a report template

Action- create an action plan per lead to easily identify tasks and responsibilities

Action- the partnership board to consider creating task groups for the actions on the implementation plan the partnership board should complete. Revisit at the next meeting.

The meeting then discussed Board Membership. The question being discussed was whether membership should be fixed in future or be open to anyone to attend as they wished.

Mary noted that the board needed greater consistency in the make-up of the Board in order to be able to take decisions on work and actions.

Having an entirely open door membership had tended to slow down progress in the past.

However, Mary did question how the Board would engage with people who were not comfortable participating in formal meetings.

It was agreed that there needed to be greater clarity on membership, greater clarity on the roles of members and greater clarity on how the views of non-members would be gathered.

Action – The latest Terms of Reference to be re-issued and the board to look specifically at membership and who might be currently missing from membership.

At the next meeting there would a further discussion on the membership and size of the Board – in particular to ensure that gaps are identified and filled.

Aubrey suggested that there might be a subsidiary group made up of people who were non-members, or who did not wish or feel able to attend the formal setting of the board, so that their views could be gathered and fed into the main board.

It was suggested that the WISH website could be used to gather views.

Action – Paul to investigate how the WISH website could be used to gather feedback

Action- Membership to be discussed at the next Board meeting.

Mary noted that there was a group of adults who did not appear to be represented on the board who could contribute to the work of the board. This group had recently spoken to Mary and had flagged the need for more adult socialising and advocacy groups as well as more employment opportunities, greater post diagnosis support and better access to mental health services. This group could benefit from being able to run their own group(s) with a little support that would enable them to contribute to the work of the Board. The Board could ask for their views on particular topics or themes.

Action- Once structure and format agreed then visit idea of reference group of interested parties and template to request how and what each interested party might wish to be involved in or to be consulted on and give clarity of expectations of the Autism Partnership Board.

AOB

Sylvia noted that the next Herefordshire Disability Utd event was on November 7 and it would cover Universal Credit and employment issues.

Mary noted that the Healthwatch Feedback was now operating and she encouraged people to use it

Next meeting

22nd January 2019 10-12:30pm, Hereford and Leominster Room, Herefordshire Council Offices, Plough Lane, Hereford