

Autism Partnership Meeting

24/07/18

Saxon Hall, Hereford

Attendees

Valerie Fitch	Parent / someone on Autistic Spectrum
Debbie Hobbs	NAS Herefordshire
Rob Gorle	ACSYL
Gill Gorle	ACSYL
Sylvia Nicholls	Hereford Disability United
Sala Siloko	Hereford Disability United
Mary Simpson	HealthWatch
Aubrey Baillie	Autism Advocate
Amanda Bell	Priory Care
Lisa Masters	Occupational Therapist
John Burgess	CCG
Carolyn Whippman	Herefordshire Council
Les Knight	Herefordshire Council
Elsbeth Dixon	Herefordshire Council
Laura Ferguson	Herefordshire Council
Paul Choppen	Herefordshire Council
John Gorman	Herefordshire Council

Apologies

Jade Brook	Herefordshire Council
Paula-Daniel Symonds	Parent
Laura Tyler	Herefordshire Council
Cllr Rone	Herefordshire Council

Introductions, Previous Minutes and Matters Arising

John Gorman welcomed everyone and them to introduce themselves.

John then recapped the previous minutes.

John said that he had not circulated the group's Terms of Reference so as not to confuse it with the updating of the Autism strategy. Once the strategy is agreed the Terms of Reference will be circulated.

Wiki-Me – Elspeth Dixon

Elsbeth introduced Wiki-Me. Wiki-Me is a digital platform that combines a simple, secure personal website and social network functions.

Wiki- Me is the blend of two digital platforms Rick's Wiki's and Multi Me. Wiki-Me helps people with disabilities and their families have their voice heard and organise their education, health and care needs. Wiki-me allows individuals to organise and manage their information with the help of their family and link up with professionals. The individual and their family can then set up a circle of people to share sections from their profile with. The Individual and their family can then manage this circle of people at their own discretion.

Wiki-Me enables communication, co-operation and joined up support for an individual's family, friends, professionals and community circles.

The service was trialled in Herefordshire last year starting with 16 children and young people with special education needs. It is now hoped to expand the number of users to around 250 so that the project can be evaluated later this year.

Currently there is no cost to users who are trialling the system. Les said Wiki-Me has been funded for two years. Les said Wiki-me is currently part of the Local Offer.

There was a discussion about topics that included:

- Possible conflict between families and adult children over ownership of content
- Authorising access
- Closing Access (e.g. when a care worker leaves)
- Best interest decisions and mental capacity
- Training on Wiki-Me for the individual and their family.

John suggested a working group be set up to look at setting local guidelines on use, access, best interests and so on.

Action – John and Elspeth to take forward

Elspeth said she would be happy to take referrals for Wiki-Me and discuss it over the next few weeks.

Action – Paul to send out the Wiki-Me flyer with the minutes.

NAS Update

Debbie said that she had been talks with Morrison's they have started doing a quiet hour every Saturday from 9am-10am.

Debbie said she had received a report by Norman Lamb MP on the Autism diagnosis crisis. Dr Norman Lamb had sent freedom of information requests to every CCG and health trust in England Debbie had noted that Herefordshire CCG or Health Trust were not one of the 22 CCGs or 27 health trusts to respond between October and December 2017. Out of those that responded Berkshire Healthcare NHS Foundation Trust had the longest waiting times for a diagnosis – 848 days for an adult and 799 days for a child (more than 2 years).

From April 2018, each health trust is required to collect the information that is needed to monitor diagnosis waiting times, but this data may have not been routinely been collecting before.

Action – Paul to issue the report with the minutes.

Debbie also informed the meeting that there was a Dungeons and Dragons group every Friday evening at Hereford Library from 5-7pm which is proving very popular with people with Autism, she said that there was also a student group now running at the Sixth Form College.

LIAG

Valerie said has been busy training detectives and new cadets in Hereford on Autism Awareness.

Autism Strategy

Laura Ferguson went through the Autism Strategy. It was agreed that a revised version would be issued with the minutes and that member would have until August 10 to send in further comments. A final revised version would then be issued by Laura by August 24.

It is planned that the strategy will be signed off on October 11

Action – Laura to check sign off dates for CCG

Feedback mechanisms – Gill Gorle noted that there were no obvious feedback loops to obtain the views of people with autism in the strategy. Laura agreed that she would speak to Gill about this

Action Laura to speak to Gill

Making Every Contact Count – Laura suggested asking a colleague from Public Health down to a future Autism Partnership meeting to discuss what this programme is about

Action- Paul to ask a representative from Public Health to attend a future meeting.

A.O.B.

Les said he has assembled a group that has been working on a new Children's Diagnostic Pathway. Once the Children's Diagnostic Pathway is finished it will be circulated amongst the members of the Autism Partnership.

Mary Simpson said Healthwatch have developed an feedback centre for people to express their opinions on the state of Health and Social care services in Herefordshire

Mary also said Healthwath also wanted to hear the experiences of people who were either living with dementia or caring for someone with dementia between now and December 2018.

Next meetings

30th of October 2018- 10-1pm, Council Chamber, Hereford Town Hall
10 St Owen Street, Hereford, HR1 2SP

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