

**Autism Partnership Meeting**

02/08/22 at 10:30-12:30pm

<b>Attendees</b>	
Name	Role
Valerie Fitch	Chair/Person on the Autistic Spectrum, ICB, Police
Laura Ferguson	ADASS Associate, Vice Chair
Bernadette Louise	Autism Champion for Herefordshire and Worcestershire, Co-Chair of Worcestershire APB
Carolyn Whippman	Senior Commissioning Officer, Community Wellbeing, Herefordshire Council
Paul Choppen	Partnership Board Assistant, Herefordshire Council
Hilary McGlinn	Operational Manager for Community Services, Autism West Midlands
Mary Simpsons	Engagement Worker, Healthwatch
Alexia Heath	Post 16 Senior Advisor Children and Young People, Herefordshire Council
Abigail North	Parent Carer, TASP
Nick Gregory	Engagement Navigator, Carer Links
Bridget McGrath	Expert By Experience, Brighfire
Rachel Johnson	Manager Community Learning Ledbury, Walsingham Support
Anna Wainwright	HVOSS & All Sorts
John Gorman	Herefordshire Council
Debbie Hobbs	Parent Carer Voice, Herefordshire and Worcestershire NAS, Expert by Experience, DOHSC
Rebecca Hill	Learning Disability Nurse, Community Learning Disability Team.
Les Knight	Herefordshire Council
Jenny Dalloway	Programme Director – Mental Health, Learning Disabilities and Autism, NHS Herefordshire and Worcestershire CCG

<b>Apologies</b>	
Name	Role
Lisa Masters	Independent Occupational Therapist
Fiona Goodwin	Consultant Community Paediatrician & Medical Adviser for A&F, Community Paediatrics
Helen George	Accommodation Support Officer, Community Wellbeing, Herefordshire Council
Lauren Keen	Crossroads
James Baker	Hereford Make/Person on the Autistic Spectrum
Rebecca Ashton	Expert by Experience
Julia Walker	Temporary Social Work Apprentice, Community Wellbeing, Herefordshire Council

Conflict of Interest Declaration

Valerie asked members if they had a conflict of interest to declare, Debbie Hobbs had one concerning the Oliver McGowan Training. Laura Ferguson raised a concern regarding herself being the Independent Foster Panel Chair for Herefordshire and the conversation about Children Safeguarding on the agenda item. Bernadette Louise mentioned her connection with Fabricated and Induced Illnesses within Autistic Families.

#### Minutes from Previous Meeting and Matters Arising

Actions			Updates
Les Knight	Action 1	To sort figures for the type of staff attending the Autism Education Trust Training.	No response, Carolyn will push
Laura Ferguson	Action 2	Laura to forward to Les the details of the two council owned farm houses on the outskirts of Herefordshire that may be suitable for the provision of secondary age autistic individuals with anxiety issues.	Laura forwarded Les Knight the revenant contact.
Paul Choppen	Action 3	To forward Bernadette's email address onto Abigail North so they can liaise	Paul completed this.

#### Affirmation of Laura Ferguson as Vice Chair

Valerie confirmed Laura as the Vice Chair with no objections.

#### ICS updates



DSfAP Programme  
Update July 2022[69].

Bernadette - Work streams for the ICB are going strong with expansion due to the work around health inequalities. Bernadette has been working with Rachael Skinner on a new video on health inequalities and the LeDeR Review for GPs. The LeDeR review now includes people with a formal diagnosis of autism as well as people with a learning disability. So far the small number of anecdotal reports from paramedics are suicides. Worcestershire APB are focusing on suicide preventions along with Public Health.

Rebecca Hill mentioning how the use of digital markers for patients (butterfly for dementia) with specific conditions can help make sure they are passed onto specific liaison nurses.

#### Sensory Friendly Environments

Valerie mentioned that the group had assessed both PCN's in Hereford and 4 of the 20 GP surgeries in Herefordshire, 10 out of 79 across the two counties. They hope to have accessed 20 surgeries by March 2023.

Valerie mentioned that the merger of GP surgeries across Hereford to form Hereford Medical Group had made it harder for patients to see the same doctor and that a lack in continuity is an issue from a sensory perspective, along with the issues surgeries are having to recruit doctors. They are currently working to persuade the landlords to put in a sensory friendly room.

Mary raised the importance of looking into the access patients have to book an appointment including the telephone system.

#### Adult Diagnostic Service - Dashboard

Valerie discussed how members of the board have been working with Worcestershire Autism Partnership Board to develop a dashboard that the ICB can fill in to see what improvements are happening including how many people are going through the diagnostic service. The dashboard is still a work in process. At the moment the hold up for the dashboard is the re-tendering process for the Autistic Diagnostic Pathway and the need to have a conversation with the chosen provider and have it written into their contract what information we expect them to gather.

Jenny has sent out an open invite to refine the specification of the 16+ Adult Autism Diagnostic Service on the 13<sup>th</sup> September from 10:30am-12pm via Zoom.

#### **Action - Paul will forward the details of the meeting to board members.**

Up for discussion at the meeting will be the current provider (The Family Psychologists) the re-tendering and re-commissioning of the Autistic Diagnostic Service and finally discussing the Autism Support Service which commenced on the 1st of August and what services will be offered to those 16+.

Valerie also raised the issue that the Family Psychologists still do not have a physical base in Hereford where they can do face to face assessments and people are still having to travel outside Herefordshire to get an autism diagnosis.

#### Autism West Midlands Hilary McGlynn



AWM Presentation  
APBs.pdf

Hilary went through her presentation, see attached. Autism West Midlands has been around for over 35 years delivering autism specific services including community based advice and support services for the past 20 years. Hilary discussed how Autism West Midlands has linked up with Brightfire CIC to develop the Autism Support Service in Herefordshire and Worcestershire.

The service is for people 16+ who have an autism diagnosis (formally and self-diagnosed) who are not eligible for support from other health or social commissioned services. This includes: social care or secondary mental health services, section 117 of Mental Health Act, CHC eligible, young people who have EHCP.

In the first year (August 2022 - March 2023) they are limiting access due to being unsure on the initial demand. They will offer post diagnosis support for those diagnosed since August 1st (service start date) with limited exemptions. The service will offer:

- Advice, information and Signposting

- 1 to 1 structured support sessions (4 sessions) run by Brightfire CIC
- Autism Confident psychoeducation programme, a group personal development programme (8 sessions) run by Autism West Midlands

The Advice and signposting can be delivered by phone/email/letter and the 1 to 1 and group support will be delivered by on-line methods initially (Zoom/Teams) with exemptions if people are unable to access online services.

In Year 2 they aim to be much more accessible opening up the service to any diagnosed/self-diagnosed person and those diagnosed prior to 1 August 2022.

They aim to publicise widely (including self-referrals), deliver services out in local communities although online offer will still be available. Offer workshops for autistic people and parent/carers in community venues and online (if required) and helping with the development of support/social groups where there are gaps.

Over the coming months they hope to develop a co-production expert by experience group comprising mostly of people who have been through the service who can help shape the service in year 2.

So far they have had 2 referrals since opening yesterday. They have appointed their year one team for Autism West Midlands which will come into place later this month, including a full time manger and two full time advisers.

John queried the issue of people receiving domiciliary care potentially being excluded from using the service. Laura also has concerns on young adults still in education with EHC plans being excluded from the service. Hilary said the issue has been raised with commissioners and individual referrals will be looked at in a case by case basis, currently referrals are being picked up through the Family Psychologists.

Hilary mentioned that there will be a crossover with the pilot online only 14-18 year old post diagnosis support service that Autism West Midlands also are running alongside Brain in Hand's app based support service.

If anyone has any queries please email Hilary McGlynn on: [hilarym@autismwestmidlands.org.uk](mailto:hilarym@autismwestmidlands.org.uk)

### Autism Strategy Carolyn Whippman

#### Priority 7:

Carolyn discussed all the priority areas:

Priority 1 - Improving understanding and acceptance of autism within society

Priority 2 – Improving autistic children and young people's access to education and positive transitions into adulthood.

Priority 3- Supporting more autistic people into employment

Priority 4 Tackling Health and Care Inequalities for Autistic People

Priority 5 – Building the Right Support in the Community

Priority 6 – Improving Support in the Criminal and Youth Justice Systems

She mentioned that a proposal had been made to add a 7<sup>th</sup> Priority which was important for Herefordshire named Keeping safe. Discussions had been had with colleagues in Worcestershire

on whether Keeping Safe should be kept on its own as Priority 7 or whether the different aspects of Keeping Safe could be absorbed into the other priority areas.

Carolyn - asked for feedback from members on whether they thought Keeping Safe should stand as its own Priority area or if it could be absorbed into the other 6 priority areas.

Valerie - mentioned that the Taskforce had come up with the proposal to include Keeping Safe as the 7<sup>th</sup> priority to highlight its particular importance for Herefordshire. Is about making sure, for example people not getting scammed and giving over their bank details.

Valerie - discussed how if the board agreed to keep Keeping Safe as a separate priority then she has got the details of the fraud squad at Nationwide and another aspect of how they try to keep their customers safe from fraud (including Posters about hidden disabilities). Another aspect is people have a tendency to trust people and by adding this priority we are keeping people safe

A discussion ensued with Laura and Mary and Bernadette and Brigit agreeing that if we are listening to experts by experience and they want Keeping Safe as a priority then it should go in and we may lose people if we don't. Mary also raised the point that Keeping Safe is a separate priority because it's about prevention, with Brigit noting the specific vulnerability autistic people have to being taken advantage of.

Mary - also noted that it is as much about where to find trusted people and support as where you can be cheated or subject to fraud. So, mental health aspect key. I know a young person with autism who has taken the message of keeping safe as 'don't trust anyone'. That makes for an awfully frightening world going forward so would want this to include positive resources, good aspects of asking for help, how to check things out etc. too. Carolyn is happy to go the consensus of board members and the Taskforce group in keeping it as a separate priority area.

Laura - also raised the issue of suicide prevention and that it would fit in strongly within priority 7 Keeping Safe. She mentioned that the Suicide Prevention Strategy for Herefordshire is due the same time as the Autism Strategy and there is potential to link both strategies and both need to imbed the lessons learned from the LeDeR work including the high number of suicides concerning autistic people.

Carolyn - said she would be happy to link up after the meeting to tally the two.

Valerie - mentioned she has also been having conversations with Adrian Symonds who is the lead for Priority 6 about co-ordinating Priority 7 Keeping Safe. She hopes to set up a meeting with him shortly once he is back off holiday.

Carolyn - is due to meet up with people around Herefordshire to see what they can contribute to the development of this priority area. Once she has go a bit more information and Valerie has had a chat with Adrian Symonds they'd both have clearer idea about responsibility for the priority.

Valerie - will take the feedback forward to the Joint Autism Strategy Meeting on 12<sup>th</sup> of September including the recommendation from members of the board and the Taskforce to include Keeping Safe as a separate (Priority 7) rather than amalgamate it into one or a few of the other existing priorities

## Priority 5

Laura also gave feedback on Priority 5 – Building the Right Support in the Community and has had conversations around housing, how successful people with autism are at getting DFG

(Disabled Facilities Grants) which is part of the Better Care Fund Allocation. She would like this considered in the strategic thinking when having conversations on Priority 5. She said we have an issue in Herefordshire as we don't have an Autism Occupational Therapist able to do that specialist sensory assessment profiling. With there being potential funding available for autistic people to get disabled facilities.

Debbie - in chat noted that Sensory OT for Herefordshire is based at Megan Baker Charity and takes private assessments.

Bernadette - raised the issue with getting DFG with Worcestershire and it is really hard to get. She also mentioned how alongside housing issues it being one of the major precursors to a crisis and that if families could be supported more they may not reach crisis point. Often even if a person for family eligible for help, the length of time it takes and the form filling can be a real issue for autistic people and families.

#### Police reports (Themes) Valerie Fitch

Valerie has had one report since the last meeting regarding an autistic person getting threatened and mistreated by neighbours due to poor fitness and hygiene and tidiness of his house of which more support could have alleviated the problem. Police have contacted social services to get the individual the support he needs. The neighbours now understand the situation and are being more supportive.

#### LD Week Valerie Fitch/Rebecca Hill

Rebecca - said it was a fabulous week with over 600 people attending events during the week. A sub group made up of people from different services across Herefordshire helped organise the week. Each day had a different theme, with the main event taking place at the Aspire Hub in Hereford due to its accessible toileting. Smaller events took place across the county.

One of the main issues that Colleen and Rebecca found came out of the event was transport which she has brought to Carolyn's attention. Specifically they were unable to provide transport for individuals to enable them to get to the various events taking place throughout the week.

Feedback has been good and they are hoping to replicate it next year although they would prefer other providers to take the lead on the event.

On the recommendation of Ian Harper the CLDT are planning on attending Aspire's Carers and Family Group Coffee Morning around Christmas time to get their views on how next year's event could be improved.

Valerie - mentioned that the feedback she got was good when she attended as part of the police/ Keeping Safe day.

#### Discussion around length of future meetings and venues Valerie Fitch

Valerie - asked members of the board for their opinions on whether to hold future meetings in person as well as online, along with having longer but less frequent meetings. Valerie recommended the Aspire Hub as a potential venue, Carolyn has sent an email to Aspire about any potential costs on using the hub.

Members had various views on what they preferred.

**Action 2 - Valerie asked Paul to collate the feedback from members on their preferred method of attendance.**

A.O.B.

CQC Oliver McGowan Training Debbie

Debbie - mentioned that she had been to a meeting in London on Monday last week where they went through a lot of detail and the Tier 1 training is ready to go but the code of practice is still being written for Tier 2 training and is not ready to be deployed.

Carolyn - re-iterated that she had spoken to Richard Keble on this and although there has been a report published on the training CQC haven't done any further work on how it's going to be rolled out. When it is ready staff numbers will have to be collated and it will have to be decided how it is scoped out.



fii autism  
hereford.pptx

Autism and Fabricated and Induced Illnesses Bernadette Louise

Bernadette - gave an overview of her presentation (see attached). It detailed an article by the Hereford Times on the 31st July asking "Is this rare form of child abuse spiking in Herefordshire" because of fabricated and induced illness by their families. The national rate is 0.2% or (1/500 of cases), however in Herefordshire the rate is 20% (60/300 cases). Bernadette aims to find out a bit more about this and the number of autistic families who have been accused of deliberately causing symptoms of illness in their child/children.

Bernadette - mentioned that data suggests there is high health inequalities in this area for autistic people, including a mix up in the labelling, including where they are talking about a fabricated and induced illness were not being diagnosed or accessed is not a diagnosable mental health condition but is called factitious disorder inflicted on another.

Bernadette - also said the NHS website is inaccurate in referring to fabricated and induced illness as Munchausen Syndrome by Proxy, where the two conditions are separate.

She went on to say how parents of children with ASD often have their parenting ability questioned, being accused of fabricating their child's symptoms or causing their child/children harm and that 1/5 mothers of children with autism and those with autism themselves report as being assessed by social services. These mothers were one hundred times more likely to be investigated for fabricated and induced illnesses.

Bernadette - asked the board for their opinions, advice and relevant contacts. If you have anything to share Bernadette's email address is [bernadette.louise1@nhs.net](mailto:bernadette.louise1@nhs.net)

**Action 3 - Laura advised Bernadette to check out the latest Ofsted report on Herefordshire Children Services and also mentioned as part of her work with ADASS she is doing research into the notion of parental blame across the east and west midlands. She suggested her and Bernadette liaise.**

Debbie - also said she would introduce Bernadette to the Autistic Parents group she runs.

**Action 4 - Alexa said she will raise the high number of families in Herefordshire accused of fabricated and induced illness with Les Knight. Although it is known within Children services and is being looked into.**

Brigit - suggested contacting Women’s Aid and other services who support women who have been subjected to abusive partners which have thrown accusations at them, report them to social services and legal processes may be able to help.

Terms of Reference

Due to time constraints this item was not discussed, Valerie agreed to sign the updated terms of reference and a copy will be sent to members of the board. If anyone has any issues with this please contact Valerie.

Next Meeting provisionally 18th October

Actions		
Paul	Action 1	Paul will forward the details of the meeting to refine the specification of the Adult Diagnostic Service to board members.
	Action 2	Valerie asked Paul to collate the feedback from members on their preferred method of attending future meetings.
Laura and Bernadette	Action 3	Laura advised Bernadette to check out the latest Ofsted report on Herefordshire Children Services and also mentioned as part of her work with ADASS she is doing research into the notion of parental blame across the east and west midlands. She suggested they liaise.
Alexa	Action 4	Will raise the high number of families in Herefordshire accused of fabricated and induced illness with Les Knight.