

Autism Partnership Meeting

18/10/22 at 10:30-12:30pm

Venue: Bromyard and Sutton Room, Plough Lane Offices & Zoom

Attendees

Name	Role
Valerie Fitch	Chair / Person on the Autistic Spectrum
Carolyn Whippman	Herefordshire Council
Silvia Nichols	Hereford Disability United
James Baker	Hereford Make / Person on the Autistic Spectrum
Abigail North	TASP
Helen George	Accommodation Support Officer, Herefordshire Council
Nick Gregory	Herefordshire CarerLink
Zoe Backhouse	Autism Specialist Advisor, Autism West Midlands
Fiona Goodwin	Consultant Community Paediatrician & Medical Adviser for A&F, Community Paediatrics
Anna Wainwright	HVOSS & All Sorts
Michelle Baillon	Person on autistic spectrum & Senior Social Subscriber, South and West Primary care Network
Alexia Heath	Post 16 Senior Advisor, Children and Young People Herefordshire Council
Paul Choppen	Partnership Board Assistant, Herefordshire Council
Debbie Hobbs	Herefordshire and Worcestershire NAS and Parent Carer Voice
Brigid McGrath	Brightfire

Apologies

Name	Role
Gill Gorle	ACSYLE
Rob Gorle	ACSYLE
John Gorman	Herefordshire Council
Chris Dunlop	Herefordshire CarerLink
Richard Clark	Senior Social Worker, Young Adults Transition Team, Herefordshire Council
Mary Simpson	Healthwatch
Richard Keble	ICS
Laura Ferguson	ADASS
Bernadette Louise	Autism Champion for Herefordshire and Worcestershire
Jenny Dalloway	Programme Director for Learning Disabilities, Mental Health and Autism, ICB
Les Knight	Herefordshire Council
Lisa Masters	Independent Occupational Therapist

Introductions

Valerie welcomed everyone to the meeting and asked them to introduce themselves. Some attendees attended by zoom and they could not see who was in the room.

Conflict of Interest

Valerie asked members if they had a conflict of interest to declare which no one did.

Minutes from Previous Meeting

Valerie went through the previous minutes.

Attendee	Action	Detail	Update
Paul Choppen	Action 1	Paul will forward the details of the meeting to refine the specification of the Adult Diagnostic Service to board members.	Paul sent this to board members
	Action2	Valerie asked Paul to collate the feedback from members on their preferred method of attending future meetings.	Paul Completed this. Around 50% wanted in person meetings, 25% preferred attending virtually and around 25% did not mind which method was used.
Laura Ferguson and Bernadette Louise	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.	Valerie will check after the meeting whether this was done.
Alexia Heath	Action 4	Will raise the high number of families in Herefordshire accused of fabricated and induced illness with Les Knight.	Alexia did raise this with Les Knight but unfortunately he was not able to come to today's meeting. Herefordshire Council has put out a press release disputing the figures raised in the Hereford Times article.

Police Reports – Valerie Fitch

Valerie said the police had received three cases in the last two months concerning autistic people.

1. A female had received nasty comments from neighbours about her being unemployed and needing a job. This case is being dealt with by the Safer Neighbourhood Team.
2. A young male in his early 20s had made friendships with the wrong crowd who have started abusing him and use him for their own ends. He is being supported.
3. Another young individual had been dealing with self-neglect issues which had resulted in neighbours insulting him about his poor hygiene. The individual has now been given a social worker to help him.

Hilary Hall – Corporate Director, Community Wellbeing

Hilary briefly popped into the meeting to introduce herself as the new Corporate Director for Community Wellbeing which covers public health, talk community all age commissioning and supported living etc. She said she hopes to come regularly to future Board meeting and formally introduce herself at the December Board meeting.

Hospital Avoidance and Dynamic Support Register – Caroline Kirby

Caroline Kirby introduced herself as the Transforming Care Lead for Herefordshire and Worcestershire ICB. Caroline is part of the complex needs team which also leads on Care and Treatment Reviews and Dynamic Support Register. She went through her [presentation](#) which is attached.

a) Current LDA beds commissioned

Valerie asked for more details about the type of people in these beds. Caroline said that all 16 were autistic and the two who are Herefordshire based one has a learning disability and the other is an autistic young person.

Caroline mentioned that they haven't had an admission from a person with a learning disability in four years with all admissions being people with autism.

Caroline also noted that they've had quite a few young people who have had an autism diagnosis while placed in tier 4 beds. In particular Individuals have gone into crisis and with risks being so high they have been unable to be cared for in the community, which has led to an admission and a subsequent assessment around needs that has included an autistic diagnosis.

The team has challenged if they feel the NICE guidance has not been followed and how an autistic assessment can be done when a person is in crisis and suffering from memories of traumatic experiences. Including two individuals receiving a diagnosis in hospital with no other family members contacted to be part of the assessment process.

The team has also been able to pick up on autistic individuals who have been admitted to a main stream mental health hospital and the staff have got the appropriate training and understand the needs of the individuals.

b) Care and Treatment Review (CTR)

Caroline mentioned CTR includes an expert by experience and an independent panel of commissioners. Her team is always present at CTR's even if they are being set and run by NHSE (Secure and CAMHS) to make sure they are working the system to support a timely discharge.

c) Dynamic Support Register

The large difference between the number of people on the DSR in Worcestershire compared to Herefordshire (125 v 28) is partly down to it being more established in the former A review of the DSR is underway to make sure everyone who needs to be on the register has been captured.

d) Herefordshire and Worcestershire DSR

Children and young people who are in commissioned 52 weeks out of county placements are also tracked. In Herefordshire and Worcestershire there are not any inpatient facilities (locked, secure or CAMHS, for Tier 4).

Funding for key workers pilot across Herefordshire and Worcestershire has been secured. The key workers will work with individuals under the age of 25 who are on amber of the DSR to try and prevent admissions.

If anyone has any further questions please email Caroline on caroline.kirby1@nhs.net

ICS Updates

LeDeR Highlight Report - covering July 1st to 30th September and updates/progress of the LeDeR programme for Herefordshire and Worcestershire.

Index	Figures
Notifications made	13 (July 6, August 1, September 6)
Reviews Completed	10 (July 0, August 1, September 9)
Notifications allocated within 3 months (ICB)	100%
Reviews completed this quarter that were within 6 months	22% See-risk section 3 focused reviews over 6 months not completed yet 8 additional reviews over 6 months not yet complete (2 are on hold because of the coroner)

There have been delays due to:

- Recruitment of Access and Support Worker post;
 - Autism friendly mental health ward environments;
 - Best practice check lists to LeDeR reviews;
 - Shared briefing to end of life care; and,
 - The Acute Trust System has to identify the deaths of autistic people which then leads to a LeDeR notification.
- a) All the delayed actions will be tracked within the report until completion and they will be addressed in the next quarter.
 - b) There will be an LeDeR learning event in January where the co-production of all the actions 23 to 24 will be consolidated.
 - c) Priority focus in the next quarter on Bowel screening access improvements.
 - d) There is now a multi-agency round table for most of the focused reviews, which has created some delay in the review progress but has made the potential for improved outcomes to be a lot greater.

Delivery Action Plan has Actions on:

- Understanding of mental capacity assessments and best interests.
- Application around best practice standards regrading pneumonia and aspiration.
- Raising awareness of preventative approaches to healthy bowel patterns.
- People with life limiting conditions and those in the last days and weeks of their lives
- Improved Health Outcomes and Health Inequalities are addressed through the reasonable adjustments criteria and the annual health checks.
- Improve the understanding of the barriers to accessing healthcare services for specific groups. This includes autistic people, people with a learning disability and those with a

minority ethnic background. It is considered that a better understanding will result in more focused interventions to improve access to help and to improve health outcomes.

- Awareness training resources to increase the number of people with an autism diagnosis which are recognised as within primary care records and a communication plan will encourage primary care networks to make notifications to LeDeR for the people with an autism diagnosis.
- Acute trust will have the means of identifying inpatients with a diagnosis of autism to ensure deaths are notified to the LeDeR system.
- People with learning disabilities and those with autism don't experience discrimination in accessing mental health and emotional wellbeing services. Physical health risk factors associated with mental health medication, will be identified, monitored and reduced.
- Autism Friendly Environments will be available in most mental health settings.
- Workforce across health and social care in our integrated system are being trained to ensure that they have more confidence and skills to make the right decisions around reasonable adjustments and to deliver personalised care because they understand peoples' needs better.

All of these actions are being tracked on a regular basis each quarter. Actions that haven't been addressed are being prioritised.

Valerie mentioned that she is part of the team of four who are doing sensory assessments at GP practices in Herefordshire and Worcestershire – 13 surgeries have been assessment and more are planned.

They have also done an assessment at Hereford County Hospitals Emergency Department which was successful. The pink room is going to have minor adjustments to better cater for people with sensory needs or autism while they await to be seen by a health professional. The hospital is setting up a taskforce group to help them make the necessary changes.

The new Adult Diagnostic Service has been delayed with a decision to be made shortly on the service provider which will commence in April 2023.

James mentioned that he was struggling to find doctors and other mental health specialists who have the required level of autism training to support him.

Action 1 - Sylvia said she would raise the issue of specialists having the in-depth autism training needed with the Mental Health Partnership meeting. Carolyn said she would raise it with her commissioning colleagues who are working on the mental health side.

Anna and Alexia asked for clarification on whether CAMHS or The Family Psychologists will be diagnosing individuals in the 16-18 year age bracket as she has individuals awaiting a diagnosis who will be too old to get a diagnosis through CAMHS soon.

Action 2 - Carolyn said she would seek clarification from Jenny Dalloway on this.

Action 3 - Paul to add Hilary Hall to the Autism Partnership Board Mailing list.

Autism Strategy Update – Carolyn Whippman

Carolyn explained that Paul had sent out an update on the Autism Strategy which was completed by Worcestershire County Council.

With regards to Herefordshire there are 7 priority areas which Carolyn and Hilary have had some local input on along with discussions around timeframes. There has been some slippage in the system due to resources and restructure. Carolyn has had meetings arranged with colleagues to

pull data from priority areas in the next few weeks and Herefordshire and Worcestershire will be meeting to consolidate findings.

Priority Area 1 - Improving understanding and acceptance of autism within society. Debbie Hobbs working with commissioners in Worcestershire as lead in this area.

Priority Area 2 - Improving autistic children and young people's access to education and positive transitions into adulthood. Les Knight is working on this. A TASK group is to be set up. Some slippage in this area.

Priority Area 3 - Supporting more autistic people into employment. Carolyn has been seeking further input in this area. Alexia has made valuable contributions and there have been conversations with Brightfire and Public Health around this area.

Priority 4 - Tackling Health and Care Inequalities for Autistic People. To reduce the health and care inequalities that autistic people face through their lives and to show that autistic people are living healthier and longer lives. In addition, to make significant progress on improving early identification; reducing diagnosis waiting times; and, improve diagnosis pathways for children and adults; so that autistic people access a timely diagnosis and the support they may need across their lives. Lead: Richard Keble ICB.

Priority 5 - Building the Right Support in the Community. John Burgess and Laura Westwood working on this area.

Priority 6 - Improving Support in the Criminal and Youth Justice Systems. Valerie mentioned this was when an autistic person has been accused and is going to court. Progressing. Lead: Nigel Webster, West Mercia Police.

Priority 7 - Keeping safe. Has been populated further and more work is being completed on this today. Carolyn has continued to meet with various individuals who can make contributions to the strategy in Hereford such as the NAS, Brightfire, Women's Aid, Intelligence Team, PREVENT, community groups, public health, colleagues, such as John Gorman, and Children services.

Action 4 - James asked Paul to share a [survey](#) on the social impact of having a market stall in Manchester for artists to enable them to have an audience to sell their work.

Cart Shed

Carolyn mentioned that the Cart Shed is a day opportunities provision near Norton Cannon in north Herefordshire which offers woodland craft and horticulture and is run by Katie Eastnor. Carolyn discussed the pilot project Being Autistic which was hosted by the Cart Shed and delivered by Brightfire.

The project's aim was to be a safe place for autistic people and to explore being autistic with other autistic adults with support by an Art Therapist and an occupational therapist. This would lead to increased knowledge and understanding of autism, focusing on positives, and develop a range of coping skills to manage difficulties.

The particular strengths were felt to be:

- Good relationships between the art therapist and the occupational therapist, lived experience of facilitators promoted sharing of experiences and vulnerabilities, enabling normalisation and acceptance of autism which they could apply to themselves and family members.
- Reflective logs indicated positive impact of the sessions and later re-evaluation via qualitative and quantitative data.

- Participants benefitted from more targeted support.

Cohorts 1 and 2 were mostly those already known to the Cart Shed, there is a waiting list of those eligible for future provision. Eligibility criteria are professional or self-diagnosis of Autism, Asperger's or ASD.

Participants fed back on their experiences which were positive, e.g. improvements in knowledge and understanding of autism; gained knowledge on use of coping skills and strategies.

The Being Autistic course offered a positive space for acceptance and exploration of autistic identity. It has been a valuable and much needed resource providing information, emotional support, practical strategies and personal insight.

Katie is looking at future funding and Brigid from Brightfire is open to rolling this type of support out to other providers.

If anyone wishes to know more about the project please e-Mail Carolyn:
Carolyn.Whippman@herefordshire.gov.uk.

Feedback on Partner Organisations

a) Local NAS - Debbie Hobbs

The NAS has started a new strategy called Moonshot which people will receive in their inbox in the next couple of weeks.

Autism Experience Bus - was fully funded by Herefordshire Council. Volunteers from HVOSS Angel were on hand to guide people through the experience on Saturday October 29th.

Oliver McGowan Mandatory Training - Worcestershire have put a bid in to be one of the providers of the service.

Timeline of rolling out the service:

- Tier 1 - November
- Tier 2 - March
- Tier 3 - TBC

As a consequence of the Social Care OFSTED report the NAS is in talks to do all of the training for Herefordshire Council and the social care teams for Understanding Autism. As soon as Debbie has a timeframe on the roll out of the training she will let Board members know.

b) Hereford Make - James Baker

James mentioned that Hereford Make specialise in blacksmithing but also have a studio that does photography, laser cutting and IT. They provide visitor session and a workplace for hobbyists, students and professionals. They can help people achieve their potential even if they have disabilities, mental health issues or super low economic output.

They know they make a differences due to a combination of case studies and questionnaires they do with wellbeing. They also have a massive social return on investment which has been peer reviewed.

James also mentioned that they are doing the gallery in Manchester to help finance support for individuals but to help people in careers, training or getting started.

Hereford Make can support people 18+ generally but can support younger people if an organisation can provide the safeguarding support needed.

c) Herefordshire CarerLinks - Nick Gregory

Nick mentioned that a lot of carers were concerned with the cost of living crisis, in particular energy costs.

The Team are trying to get some Autism Awareness Training and keeping an eye on the Oliver McGowan Mandatory Training.

People can refer to Crossroads together at www.crossroadstogether.org.uk

Action 5 - Nick will send referral forms to Paul to send out to members.

d) Brighfire - Brigid McGrath

Brigid mentioned that she had been providing one day a week support in the Being Autistic Programme which is hosted by the Cart Shed as previously mentioned.

Support for the Community Autism Service for Herefordshire and Worcestershire is running and they have been seeing people on a one-to-one basis now for the past six weeks who have had a diagnosis and who require after post diagnostic support.

e) Hereford Disability United - Sylvia Nicholls

Sylvia mentioned that face to face meetings have begun again. HDU has been going for 11 years and they had an open day in Kindle centre where Hilary Hall came to speak and there were a lot of issues around carers neglect. Often not knowing where to turn.

Amy Pitt also spoke to them about Talk Community. She mentioned that the day opportunities provision may be on the Talk Community website. Sylvia noted that not many people use the website instead relying on word of mouth, notices and other methods. She said there was a lack of access to information on what is in their local community for people not using the internet.

She said carers often wanted people to signpost them rather than having to use a computer, sometimes due to lack of trust. They would rather have something in their hand they can look through and share with others rather than on a computer screen.

Valerie mentioned that through using the internet you are isolating some people.

f) TASP – Abigail North

Abigail mentioned things were on hold at the moment.

A.O.B

a) ADASS - Laura Ferguson

Valerie mentioned that Laura hopes to bring a presentation to the board for our next meeting. Laura will be sending a survey out to people about autism and parental blame which she would like members to fill in and share.

b) Late Diagnosis in Women and Girls

Valerie mentioned this article in the recent Autistic Society's Newsletter called Your Autism. She asked Paul to send this out to Board members.

c) South West Population Public Health Academy

Valerie mentioned this webinar on Learning Disability and Autism Programme on 25th October and asked Paul to send out the flyer to Board members.

d) No Wrong Door

James mentioned that HVOSS is looking to replace this service which has recently ended. He asked the Board to link up with Will Lindsey to discuss what the new service would look like.

e) Women's Aid – Carolyn Whipman

Carolyn gave feedback from speaking to Helen Richardson from Women's Aid about some of the feedback staff had received though the experiences of autistic parents and children who have suffered abuse.

- Autistic children experienced settling into a new environment and routine if they have to move to refuge. Women's Aid are redesigning their refuge so there are quieter spaces with them as well as expanding accommodation provision through the county.
- The high level of need of the autistic child made it hard for mum to find the time to access support for herself.
- Not being able to take familiar comfort items from home made it hard for the children to settle.
- Difficulty changing schools and in some cases remaining at the school from the area they had fled so as to maintain routine and avoid agitation. There was also the issue of availability of suitable placement space in a specialist school in the area women fled to.
- Sometimes clients have had to remain in fleeing address due to her children being autistic and had to get legal representation for an occupational order because displacing children and having to move equipment would have been more difficult. This meant that the perpetrators know where partner was, although safety measures were put in place.
- Other impacts of this kind of scenario, effect on working hours, mortgage, buying out etc.

Working with Survivors/Victims who have autism:

- There are examples of clients abused by partners becoming agitated and not able to deal with stress of the police being called and can get aggressive with police and get themselves arrested. This kind of reaction can often be abused by perpetrators for their own gains.
- There is always a huge financial implication as well as emotional toll on clients with autism.
- Risk assessments and support planning need to be approached differently. Verbal bullet points and direct questions worked best. Asking from the start how the client would like to be spoken to and helped.
- Often autistic clients find it much more difficult to understand that a relationship should not look like this as unable to read triggers in the same way.
- Lack of education, healthy relationships may not be taught in an accessible way in school.

- Perpetrator often use different control tactics. If the victim likes routine then they will deliberately change the routine to de-stabilize them. The victim cannot process the emotions and non-verbal cues so it escalates into physical violence quickly. The victim cannot pick up on the signs of tension building and emotions changing.
- Lack of answers can be seen as not cooperating.
- Sometimes the client can present as very verbally aggressive and can get confused easily.
- Therefore, their story can get manipulated easily. They can seem as if they don't want to engage.
- They can't easily access support group support as they don't understand the group dynamics. 1-2-1 tailored support is required.

Valerie said she hopes to get the police to do the Oliver McGowan Mandatory Training so they have a better knowledge of what being autistic is like.

Action 6 - Paul to send out Late Diagnosis in Women and Girls article in the Autistic Society's newsletter Your Autism.

Action 7 - Paul to send the flyer to Board members.

Action 8 - Valerie asked James to send Will's details to Paul.

Next Meeting

Attendee	Action	Detail
Sylvia Nicholls, Carolyn Whippman	Action 1	Sylvia said she would raise the issue of the specialist autism training with the Mental Health Partnership meeting. Carolyn said she would rise it with her commissioning colleagues who are working on mental health side.
Carolyn Whippman	Action 2	To seek clarification from Jenny Dalloway on whether 16-18 year olds will be diagnosed by CAMHS or Family Psychologists.
Paul Choppen	Action 3	Add Hilary Hall to the Autism Partnership Board Mailing list.
	Action 4	To share a survey on the social impact of having a market stall in Manchester for artists to enable them to have an audience to sell their work.
	Action 6	To send out Late Diagnosis in Women and Girls article in the Autistic Society's newsletter Your Autism
	Action 7	To send out the details of the South West Population Public Health Academy webinar on Learning Disability and Autism Programme on 25th October
Nick Gregory, Paul Choppen	Action 5	Nick will send referral forms to Paul to send out to members.
James Baker	Action 8	To send Will Lindesay's contact details to Paul in reference to discussing what should replace the No Wrong Door Service

13th December 12pm - 2pm in the Fownhope room at Plough Lane Offices. Details will be sent out in due course.