

Autism Partnership Meeting

23rd April 10 am – 1 pm

Venue: Mordiford Room, Plough Lane Offices & Microsoft Teams

Attendees

Name	Role
Valerie Fitch	Chair/Person on the Autistic Spectrum
Paul Choppen	Partnership Board Assistant, Herefordshire Council
Glen Crosier	Senior Commissioning Officer, Community Wellbeing, Herefordshire Council
Anna Swift	Lead for Neurodivergent Children & Young People NHS Herefordshire and Worcestershire
Sylvia Nicholls	HDU – Hereford Disability United
Laura Ferguson	ADASS WM, Vice Chair, Parent of Autistic Adult
James Baker	Person on the Autistic Spectrum/Hereford Make
Mary Simpson	Healthwatch
Dr Marisa.Lewis	Independent Psychologist, Marches Psychological Services
Dave Andrews	Senior Telecare Advisor, Herefordshire Council
Tracy Harley	Social Worker, Herefordshire Council
Kay Mayes	Autism West Midlands
Rachel Oakley	Walsingham Support
Alexia Heath	Post 16 Senior Advisor, Children and Young People, Herefordshire Council
Henry Webster	Autism West Midlands
Zoe Bristow	Autism West Midlands

Apologies

Name	Role
Jack Caine	Senior Programme Lead – Learning Disability and Autism NHS Herefordshire and Worcestershire
Debbie Hobbs	Parent Carer Voice /Local NAS
Brigid McGrath	Brightfire CIC
Katie Labbett	M.E.A.M. Multi-agency Strategic Lead, Herefordshire Council
Rebecca Antrim	Person on the Autistic Spectrum
Katie Eastaugh	Cart Shed
Caroline Jones	Social Care Assessor, Herefordshire Council
Hilary Jones	Head of Additional Needs, Children and Young People, Herefordshire Council
Alex Fitzpatrick	Cart Shed
Sally Wilson	Head of Care Commissioning, Community Wellbeing, Herefordshire Council
Helen George	Accommodation Support Officer, Community Wellbeing, Herefordshire Council
Marie Bridgewater,	Hate Crime Officer., West Mercia Police
John Burgess	Senior Commissioning Officer, Community Wellbeing, Herefordshire Council
Zoe Cottrell	Team Manager, CarerLinks

Name	Role
Josh Swinson-Davis	Spectrum Days
Bernadette Louise	Autism Champion
Roz Pither	Head of Additional Needs, Children and Young People, Herefordshire Council
Julie Kerin	Social Worker, Community Wellbeing, Herefordshire Council
Ryan Statton	Head of Communities, Halo Leisure
Nick Gregory	CarerLinks
Hilary Hall	Corporate Director Community Wellbeing, Herefordshire Council

Introductions and Apologies

Valerie welcomed everyone and asked for introductions.

Conflict of Interest

No one declared a conflict of interest.

Minutes and Actions from Previous Meetings – Valerie Fitch

Valerie then went through the actions from the previous meetings.

Outstanding 2023 Meeting Actions

Attendee	Action	Detail	Update
Paul Choppen	1	Will see if Ryan wants to discuss swimming lesson for people with autism at the next board meeting.	Ryan was unable to attend this meeting but hopes to attend a future meeting.
Valerie Fitch	2	To ask whether an autism tick box could be added to the Compact system to the chair of the National Missing Focus group.	Lyn has retired, Valerie is still looking to arrange a meeting with her replacement lead on hate crimes PC Marie Bridgwater Marie Bridgewater, this is now an action taken forward.
Anna Swift	3	Anna said she needed to raise with her ICB and PCN colleagues the need for the appointment booking form to be easily accessible on the surgeries websites.	Anna mentioned how the different surgeries and PCN have different website UIs. However the new GP Lead will work with all PCN's to improve their accessibility.

Actions from the 16th of January

Attendee	Action	Detail	Update
Glen Crosier	Action 1	To have a discussion with Haley Doyle and other colleagues about whether a presentation on the Joint All Ages Autism Strategy is needed when it goes to Cabinet.	Cabinet has approved the Autism Strategy but there will still be a presentation given to the Health and Wellbeing Board by Valerie Fitch.

Attendee	Action	Detail	Update
Glen Crosier	Action 2	Check that the changes requested to the Autism Strategy at the strategy sign off meeting on the 28th of November have been made.	Glen said the design team will check that these changes have been made.
Valerie Fitch	Action 3	Valerie to liaise with PC Marie Bridgwater to obtain Hate Crime information against autistic people and also to see if she would attend our meetings in future.	Lyn has retired, Valerie is still looking to arrange a meeting with her replacement lead on hate crimes PC Marie Bridgwater Marie Bridgewater.
John Gorman	Action 4	To find an ART contact (Advice Referral Team) for James to liaise regarding helping at Hereford Make having their needs assessed.	As John has left the council. Tracy Harley said she would contact the ART Team to find out how they can help with accessing people's needs including accommodation and also how they can link better with the colleges / day services.
James Baker and Helen George	Action 5	James and Helen to liaise regarding the best person to help with the accommodation needs of service users at Hereford Make.	Paul was also asked to add the ART contact details to the Autism Partnership Webpage.
Paul Choppen	Action 6	Add ICB Local Authority Schools and the Parent Carer Forum, Partnerships for Inclusion of Neurodiversity (PINS) in Schools to the next meeting's agenda. Debbie also asked Paul to contact Anna Swift for information that can be sent out to APB members.	Anna is in the process of creating a newsletter which will summarise the priorities of the children's work around neurodiversity and new projects services which are being developed. This is added to the agenda for April. The first one will include details of the project Partnerships for Inclusion of Neurodiversity in Schools. Anna is creating a database of people to circulate this and will include Paul to circulate to the APB in Herefordshire.

All-Age Joint Autism Strategy Update: Glen Crosier / Valerie Fitch

Glen discussed how Cabinet had approved the Autism Strategy and the Strategy will now be presented to the Health and Wellbeing Board. The design team is currently making finishing touches to the Autism Strategy including implementing the changes requested by Board members at the sign off meeting on November 28th last year.

Action 1 - Valerie will send the finalised Autism Strategy, when available to Paul, he will forward to Board members.

Making Every Adult Matter (MEAM) Katie Labbett – Herefordshire Council

Katie was unable to attend.

Action 2 – Paul to add to the next agenda.

Partnership for Inclusion of Neurodiversity in Schools (PINS) - Anna Swift – Integrated Care Board (ICB)

Anna explained the funding was to support the neurodivergent pupils in 36 primary schools across Herefordshire. The funding will enable schools to have a suite of support available to them. The schools on board will each complete a self-assessment tool to identify what is being done well and what needs to be improved. A £1000 has been allocated per school for support provision. Additionally a suite of support will be put together by the ICB that can provide multiple schools with support from the steering group and the therapy team, the specialist teacher locally or purchased.

Between now and September support needs will be identified and decisions on how those needs can be met will be made. The support will then be implemented between September to July school year.

Parent Carer Voice will provide support to the schools to help identify the support needed. They hope mentors can share learning with other schools across Herefordshire and Worcestershire.

A steering group has been set up to identify what support is needed. The group includes:

- Hilary Jones (Head of Service / Service Manager - Additional Needs)
- Debbie Hobbs (Parent Carer Voice)
- Elizabeth Kearns (Head Teacher, Hampton Dene Primary School)
- Della, Pascoe (Early Years SEND Inclusion Service Manager)
- Representatives from NHS Therapy Teams
- Representatives from CoSI Social Interaction Services and leads from the ICB.

Monthly meetings have been booked in until next April.

Regarding the governance structure, the steering group will report to the Children's and Young People Delivery Group who will report to the Learning Disabilities and Autism Assurance Board which is led by Jack Caine and Richard Keble.

Anna expressed her desire to get young people involved in giving feedback on the project. James suggested that Anna link in with the Youth Provision Board run by HVOSS.

Action 3 - James will share the contact information with Anna after the meeting.

Police Hate Crimes reports (Themes) - Valerie Fitch

Valerie hadn't received the Hate Crime Reports from the Police to share with the Board.

ICS updates - Anna Swift – Integrated Care Board/Valerie Fitch

Anna went through the latest updates from the ICB including: Annual Health Checks, Sensory Friendly Environments, Reasonable Adjustment Digital Flags (RADF), Review – Accessibility of

Mental Health Services Autistic for People and Neurodivergent Children & Young People's Programme. Please see attached.

Anna mentioned that Jack Caine is leading on the Sensory Friendly Environments in Herefordshire taking over from Richard Keble.

Laura said she would share some links to national research on supporting people and their families pre-diagnosis from Autistic and ADASS with Anna.

Valerie mentioned that her son was in one of the videos made by Taurus Healthcare on patients going to have their annual reviews. Valerie along with her son will be attending the ICB meeting next week where the video might be shown, If anyone would like to have the link to the video please email her.

Landline Digital Switch Over Concerns - Dave Andrews (Senior Telecare Advisor, Community Wellbeing) Technology Enabled Care/Technology Enabled Living.

Dave mentioned that there were over 2,000 people across Herefordshire using telecare provided by the Council. Telecare is an impendent alarm and equipment that when triggered send a signal to a base unit which subsequently calls a call centre who respond to that trigger.

Dave explained that the big issue is the switch from an analogue telephone system to digital. He explained on switching to digital telephone service including the loss of connectivity in the event of a power cut compared to analogue without new equipment being installed.

A programme of work is underway to change over every single piece of telecare equipment provided over the past 20 years to a newer digital form that will work when the digital switch takes place. BT Openreach have been tasked with having everyone switched over to fibre optic lines by the end of 2025. He further discussed the issues around the need to replace the older copper cabling with higher bandwidth fibre optic cabling, installing new telecare equipment capable of using the cellular network in times of power cuts or broadband issues and the need to have more of Herefordshire covered by the mobile networks.

Dave also mentioned that charges will be increased to accommodate the added costs. Individuals with telecare equipment should notify their call provider that they are a vulnerable person and therefore should not be changed over to digital without consultation.

A newsletter is being worked on which will be sent out shortly to explain the situation to those affected, a digital version of this newsletter will be shared in due course, it will also be available via the Council's website.

Dave is also happy to be contacted should anyone have further questions or concerns. His contact details are: Email: Dave.Andrews@herefordshire.gov.uk: Tel: 01432 383793

Sylvia asked for letters quoting the increased telecare rates to be based on the monthly cost in line with their billing by Hoople rather than the current weekly basis.

Action 4 - Dave will liaise with Hoople on the issue.

Autism assessments - some challenges and recent findings (high functioning girls) - Laura Ferguson/James Baker

James explained how Laura and he had supported a young lady from Hereford Make to have an additional assessment and get an autism diagnosis. Laura and James co-wrote a letter detailing high level of knowledge of the diagnostic process, some mitigating factors and issues with the original assessment. James and Laura highlighted some of the learning from the original assessments and the reasonable adjustments that helped the lady finally get an autism diagnosis. Issues highlighted included:

- Originally not being offered an assessment locally. This decision caused undue stress compromising the original assessment.
- Masking by the individual not being picked up. Issues that led to masking included: the effects of medication not being taken into account, not being offered a quiet space and the presence and bias of the individual's mother who did not want her daughter to be diagnosed
- The lack of advocacy support- Individuals should be able to bring their own chosen advocate with them to the assessment or be offered one. Their advocate shouldn't have to be a family member.

James also explained how, due to the lady's complex needs, the previous assessors hadn't gone into separating what was behaviour due to OCD and behaviour due to being autistic partly down to the masking at the previous assessment.

Laura and James discussed how as a Board we need to look at how organisations can support people following an unsuccessful autism diagnosis including challenging the result of an assessment. Laura also mentioned how the ICB as commissioner could really benefit from having more feedback on people's experiences of the diagnostic process (particularly from those on the fringes).

Valerie also mentioned the work we all need to do on challenging people's negative perception of being autistic.

Action 5 - Laura and James agreed to share the learning as a case study with Anna.

Anna mentioned the ICB is planning to commission a service specifically for children and young people aged 0-18 to support their needs relating to getting a diagnostic assessment and mental health provision. The service will also have better transitional arrangements into the adult assessment space.

The ICB is also look at developing a support service for children and young people. The ICB is currently mapping what support is currently available and what additional support is needed. Anna invited Laura to be part of this process. The ICB is also looking to work with Autism West Midlands to improve the range of advocacy support available.

Valerie asked Zoe Bristow to give a brief overview of the courses Autism West Midlands run.

Zoe gave a brief overview of the courses Autism West Midlands currently offers, this includes:

- *1:1 Information, Advice and Guidance Sessions*. A series of 4 person-centred sessions with one of their autism advisors.

- *Autism Confident Programme* -This is a free 8-week programme which aims to help individuals understand more about autism, improve their confidence, and provide an opportunity for individuals to meet other autistic people. It also offers opportunities for individuals to develop their social skills in a supported group setting.
- *Teen Autism Confident Programme*. This programme was launched this year in Herefordshire and is for individuals age 13-17 years old. The programme is open to teenagers with an autism diagnoses.

For more information on the services Autism West Midlands run see:

<https://autismwestmidlands.org.uk/what-we-do/community-support-services/herefordworcs/>

Autism West Midlands can also be contacted on: herefordworcs@autismwestmidlands.org.uk and by phoning 01905 671953 or 01432 801687.

Teens Autism Confident Course and update – Zoe Bristow Autism Westmidlands

Zoe mentioned that from the three *Teen Autism Confident Programme* sessions that have occurred feedback from parents is the lack of understanding of autism within Schools. Students were particularly having problems managing their sensory overload needs in school as they would at home. An example of this was teachers not always allowing the use of fiddle items in class.

Zoe also asked members on the Board to help fill in a *Co-Production Survey* on what social groups, peer groups and support groups would be beneficial to autistic adults in Herefordshire. James suggested Zoe send the survey to the colleges to get student feedback.

Action 6 - Valerie asked Zoe to forward information on these Autism Confident Programmes to Paul so it could be shared with Board members.

Feedback from Partner Organisations

a) Brightfire CIC

Brightfire have received funding from the Herefordshire Community Foundation for a pilot project called the *Auti Social Club*. This is a social connection project run by and for autistic adults based in Hereford.

Autistic adults who would like to join the project as participants, volunteers or as members of the steering group should contact Brightfire through the link on their website.

Please see <https://www.brightfirecic.com/social-connection> for more information.

Action 7 - Paul to send out the link to this project to board members.

b) Hereford Disability United

Sylvia noted that during a Mental Health Partnership Event for people up to the age of 30 one of the speakers used a phrase in her discussion saying “There appears to be an epidemic of autism” which some in the autistic community thought it related to meaning autism is infectious like a disease, while some professionals and practitioners thought it referred to false diagnosis taking up resources.

Subsequently Sylvia and the speaker in question both sent out a letter of apology to everyone that attended regarding no offence had meant to be caused by the phrase “epidemic of autism”.

Following on from this Silvia has been contacted by the Herefordshire and Worcestershire Wellbeing Recovery College that is concerned with mental health and how to approach it. After discussing the incident they decided it would be beneficial to get a better understanding of how people interpret language.

Silvia is therefore going to set up a group through the Making It Real Board to look at developing a video course on how people interpret language. The group will be meeting at the Aspire Hub on Tuesday the 21st May from 12-2pm, anyone is welcome to attend.

Valerie also reminded Board members that if they had any event, group or information they would like to disseminate to contact Paul on paul.choppen@herefordshire.gov.uk

A.O.B.

Dr Marisa Lewis introduced herself, explaining she is a psychologist working in independent practise in Hereford. She explained how she has worked with autistic individuals, children and adults, for 17 years assessing, diagnosing and providing psychotherapeutic support. This included years of experience working in the NHS and Welsh Government on developing autism services and within the assessment process.

Dr Lewis explained her desire to network and find out what services were available in Herefordshire for her clients and the families she is working with. She also wanted to know the current position within health, social care and education regarding independent providers providing assessments.

If you would like to get in contact with Dr Marisa Lewis please contact her at marisa@marchespsychologicalservices.co.uk

Action 8 - Anna said she would find out when the contract for the autism diagnostic provider, which is currently the Family Psychologists, will next be up for tendering.

Laura suggested Dr Marisa Lewis register as a supplier with the NHS trust. Procurement /Tendering <https://www.hacw.nhs.uk/quality-and-safety/procurement-1001/> EU tendering Portal https://uk.eu-supply.com/login.asp?B=HACW_NHS

Date of next Meeting

16th July 10:00 am -12:30 pm, Mordiford Room, Plough Lane Offices/MS Teams

Actions

Attendee	Action	Detail
Valerie Fitch / Paul Choppen	Action 1	To send the finalised Autism Strategy, when it is available, to Paul who will forward on to Board members.
Paul Choppen	Action 2	Paul to add making Every Adult Matter item to the next agenda.

Attendee	Action	Detail
James Baker/ Anna Swift	Action 3	James suggested that Anna link in with the Youth Provision Board run by HVOSS regarding youth involvement within PINS (Partnership for Inclusion of Neurodiversity in Schools). James will share the contact information with Anna after the meeting.
Dave Andrews	Action 4	Sylvia asked for letters quoting the increased telecare rates to be based on the monthly cost in line with their billing by Hoople rather than the current weekly basis. Dave will liaise with Hoople on the issue.
Laura Ferguson / James Baker	Action 5	Laura and James agreed to share the learning from their case study with Anna. This is regarding the case they shared with the board regarding an individual's journey to getting an autism diagnosis after challenging the result from the original assessment.
Zoe Bristow / Paul Choppen	Action 6	Zoe to forward information on the Autism West Midlands projects to Paul so it could be shared with Board members.
Paul Choppen	Action 7	Paul to send out the link to the Brightfire Auti social connection project with board members.
Anna Swift	Action 8	Anna to find out when the contract for the autism diagnostic provider, which is currently the Family Psychologists, will next be up for tendering.