

**Autism Partnership Meeting
26th October 10:30am-12:30pm
Meeting Venue: Zoom**

Attendees:

Valerie Fitch	Chair / Person on the Autistic Spectrum
Laura Ferguson	Herefordshire Council
John Gorman	Herefordshire Council
Paul Choppen	Herefordshire Council
Mary Simpson	Healthwatch
Debbie Hobbs	Herefordshire and Worcestershire NAS / Parent Carer Voice
Helen George	Herefordshire Council
Jenny Dalloway	Herefordshire and Worcestershire CCG
Brigid McGrath	Brightfire Holistic
Alexia Health	Herefordshire Council
Julie Walker	Herefordshire Council
Louise McEvoy	Public Health
John Burgess	Herefordshire Council
Richard Keble	Public Health

Apologies

James Baker	Hereford Make
Rebecca Ashton	Person on the Autistic Spectrum
Rob Gorle	ACSYLE
Gill Gorle	ACSYLE
Les Knight	Herefordshire Council
Rachel Johnson	The Family Psychologists

Introduction

Valerie introduced herself and asked John to go through the actions from the previous board meeting and subsequent planning meeting.

Previous Minutes, Matters Arising and Actions

August 17th 2021

Action 1 - Autism Awareness Staff Training Content – Richard to pull together the health and social care leads to discuss what Autism Awareness training can be provided to NHS and Council Staff.

There was no update from Richard Keble as he joined the meeting late. Jenny reported that the Tier 1 Oliver McGowan training has taken place and the benefits of the training will be reviewed. Valerie will discuss the training with Richard when she next meets him.

Action 2 – Debbie to clarify how the Board can feedback to the NAS Policy Team - see agenda item.

Action 3 - Paul to invite Karen Capewell to a future meeting to discuss the review of complex care packages including re-allocation of funding with CCG. Paul will invite Karen to a future meeting.

Action 4 - Valerie and Laura to liaise about the Taskforce groups' feedback regarding the recommendations outlined in the National Autism strategy for Autistic Children, Young People and Adults- see documents attached for feedback.

Action 5 - Laura to chase Richard about extending the Speak Easy Now service (LD) to Herefordshire – (out of scope of this meeting).

Agenda

National Autism strategy for Autistic Children, Young People and Adults: 2021 to 2026, How the Autism Partnership Board comply with the strategies recommendations - Valerie Fitch

Valerie highlighted the main points from the Taskforce's feedback (See attached).

Valerie mentioned the taskforce felt that priority 5: Building the right support in the community was the most important priority with priority 1: Improving understanding and acceptance of autism within society; being a close second.

Laura suggested she discuss with the Talk Community team how the Board could engage with them to push its agendas.

Action 1 - Valerie also asked Laura to find out if they could send a representative to future Board meetings.

In regards to priority 6: Improving support within the criminal and youth justice system: Valerie hoped to use her links with the Police to partake in relevant groups and get a person from the Justice System to come and talk to the Board about how they deal with people on the autistic spectrum who are the victim of a crime or the perpetrator.

Valerie highlighted issues the Board had in getting the views of young people and parents. Valerie hopes to get more engagement from younger people and parents by setting up taskforce meetings in the evenings and then feedback their views to the Board.

Autism Champion – Jenny Dalloway

Jenny discussed that the CCG were recruiting an Autism Champion (2/3 days a week/6 months role) to work with Boards (at director level) to ensure services are being developed for autistic people and making sure services that are in place can support autistic people across Herefordshire and Worcestershire. The Champion will deliver a report at the end of the financial year on what areas need to be focused on to improve outcomes for autistic people.

Autism Service Specification – Integrated Care Service – Adult Diagnostic Pathway - Jenny Dalloway

Jenny mentioned how the current contract with the Family Psychologist ends in March 2022 and that the CCG are going through the procurement process to secure a provider for the adult diagnostic pathway from April 2022. The aim was to manage the existing backlog with the current

provider separately, so the new provider start can start afresh. They are also going out to tender for a support service for young people and adults to start from April as well.

Debbie offered up Hereford NAS's office at the Fred Bulmer Centre as a venue for future diagnostic clinics so that they could be held in Herefordshire as was promised with the current procurement.

Jenny held a discussion with the Board about what members thought were the most important aspects to get right when recommissioning for a provider for the adult diagnostic pathway. Jenny asked members what they thought the most important aspects of the pathway were. Members responded with the following comments:

- **Waiting Times** - Making sure the individual understands the steps and length of time it may take to complete the pathway and get a diagnosis.
- **Long term support for families** – emotional and practical support for the family members who are assisting the individual in going through the pathway.
- **After care Support** - support and signposting for individuals who don't get a positive autism diagnosis.
- **Location** - Making sure the service is Herefordshire based and takes into account the rural complexities including lack of transport.
- **Links to GP Practices** - including how a GP will be informed when one of their patients has received a diagnosis and made aware of the relevant signposting/links available.
- **Clearing the Backlog** - dealing with long waiting times. Investigating what is the reason for the long waiting times.

Jenny then asked how much support should be provided by the diagnostic pathway as opposed to the post diagnostic support service. She said the current thinking was to have a service that is clinically focused on providing a diagnosis and a separate support service.

Members mostly agreed but made various points:

- For the individual the journey matters more than the process.
- The diagnosis service should offer support for the family and the referred individual around going through the process and coming to terms with the diagnosis. While the supports service should offer practical support around living with autism and relevant signposting.
- Support for parents to help them explain the diagnosis to their children and allay any fears and misunderstandings they may have and how they will be supported.
- People should be able to dip in and out of support as needed.

Jenny then thanked everyone for their views and said that they are currently developing the specification and advertising as well as planning a market engagement event in early December around the support service. The expectation is that they will be receiving the proposals from providers in January.

Police - Valerie Fitch

Valerie discussed how an autistic person has had to move out of his flat and live with their parents due to harassment and trespassing of a perpetrator.

Valerie also mentioned she was registered as an Appropriate Person for an autistic person with the police. She discussed an incident in which a person was beaten up and the police had failed to follow due process including:

- failing to note the person as being autistic on the crime report;
- not asking the victim for a statement;
- closing the case without asking the victim what they wanted to happen; and,
- the victim has not been given a victim support leaflet on how to deal with the incident.

The case has been brought to the attention of the superintendent and the police have apologised to the individual. Valerie will raise the incident at the next LIAG meeting.

Suicide Prevention – John Burgess and Louise McEvoy (Senior Commissioning Officer, Adult and Communities, Herefordshire Council and Louise McEvoy Lead on Suicide Prevention Programme, Worcestershire County Council)

John introduced himself and mentioned one of the roles he covers is around mental health including alongside Louise on Suicide Prevention. Louise discussed how she is working across Herefordshire and Worcestershire on the Suicide Prevention Programme which was funded by NHS England for 3 years and was approaching the end of year 1. She works alongside her colleagues Mark Dillow and Caroline Kingston who are community development workers.

Louise talked the board through her presentation of her main work streams. See attached.

Mary queried who was pushing the increasing diversity, hate crime and prevent agendas in council now that Neville Meredith has left.

Alexia said that Paul Smith is the Acting Director for Adults and Communities and responsible officer for the local authorities' approach to the Prevent. Ewen Archibald (Interim Director for All Age Commissioning) is the lead officer on Prevent programme. Meanwhile Harriet Yellin and Carol Trachonitis lead the council's corporate approach to equality and diversity. Alexia highlighted that the discussions would have to be had with Ewen regarding choosing a representative from the Prevent panel to attend the Autism Partnership Board meetings.

Action 2 - Alexia to keep the board up to date on who will replace Paul Smith as the Director for Adults and Communities which is being currently advertised.

Sustainability and Transformation Partnership - ICS Low Stimulus Environments Roles

Valerie Fitch and Rebecca Ashton along with representatives from Worcestershire have had their expression of interest accepted for roles in setting up the low stimulus environments within primary care networks. An occupational therapist with expertise in sensory assessments and environments will assist them in assessing potential sites,

Feedback to the NAS Policy Team – Debbie Hobbs

Debbie said due to the merger of the Hereford and Worcester NAS branches the mechanism in which the board feedbacks to the NAS Policy team has been delayed. Debbie will be chairing the Hereford and Worcester branch once the merger is complete.

The Policy Team had just finished their segment for the SEND review which is being collated and put back into the system.

Hereford NAS

Valerie highlighted that over the past 6 months Debbie has answered and received over 867 email requesting help and support. Mary highlighted the amount of emails and social media posts

Debbie and her colleagues have to respond to should go down if the Diagnostic Pathway and Post Diagnostic Support Group is successful. Mary asked for this to be highlighted in the KPI spreadsheet.

Action 3 - Valerie/Laura to add the amount of enquires to the local NAS branch as a KPI to the Diagnostic Pathway and Support Service KPI spread sheet.

Debbie has also started a conversation with the Council on a pathway for children that don't fit in to main stream schools. She has also highlighted the Autism hub as being up for discussion with Les Knight and a few other partners and commissioners.

Debbie also asked that as she has admin support from the NAS, people wanting to email her directly should use her specific email address (debbie.hobbs@nas-volunteers.org.uk) rather than the branch's email address.

A.O.B.

Hereford Make Disability Awareness Session - Valerie reminded members that the disability awareness session at Hereford Make was still due to go ahead on the 6th of December from 13:30 – 16:30. Hereford Make's address is: Unit 1-3, 2 Harrow Road, Hereford, HR4 0EH.

Children's and Families Strategic Improvement Plan - Debbie had issues with the plan which is going to full Council cabinet. Debbie wanted it noted that there was no mention of autistic children. She will be speaking to Les Knight about it.

<https://www.herefordshire.gov.uk/news/article/1244/herefordshire-s-children-s-services-improvement-plan-endorsed-by-cabinet>

It was suggested that Debbie contact Dianne Toynbee the Cabinet member for Children's and Family Services, and Young People's Attainment.

<https://councillors.herefordshire.gov.uk/mgUserInfo.aspx?UID=50003520>

Terminology - Brigit said it would be a good idea for the board to do a piece of work around the constancy of terminology regarding autism, including how language affect self-esteem and the constancy of terminology across different bodies and the outdated terms used.

Action 4 - Laura asked Brigit and the Taskforce group if they could suggest some feedback on autism terminology in time for the January meeting.

Next Meeting

Valerie said the next board meeting will be January.

Update -The next meeting has been scheduled for January 11th from 10:30am-12:30pm. Details will be sent out in due course.

Valerie asked for suggestions for subjects for the next meeting.

Autism Training Update - suggested by Mary. Valerie pointed out that the Oliver McGowan training will be starting in April and expected Autism Training to be discussed at the April Meeting. ICS projects - Jenny said herself and Richard Keble had committed to update the Board on a range of projects at each meeting.

Talk Community - Laura suggested inviting a representative from Talk Community to the next meeting to discuss in broader terms what the delivery plan and opportunities where it links in with work we are trying to achieve.

Engaging with people who don't access the Internet - Valerie recommended this item.

Update on the KPI for the Diagnostic Pathway and Support Service spread sheet- Valerie and Laura to update.

Actions

Name	Action	Detail
Laura	Action 1	To discuss with the Talk Community team the best way the board could engage with them to push the board's agendas. Laura to also ask if they could send a representative to future Board meetings.
Alexia	Action 2	To keep the Board up to date on who will replace Paul Smith as the Director for Adults and Communities which is being currently advertised.
Valerie/Laura	Action 3	To add the amount of enquires to the local NAS branch as a KPI to the Diagnostic Pathway and Support Service KPI spread sheet.
Brigit/Valerie	Action 4	Brigit and the Taskforce group to suggest some feedback on autism terminology for the January meeting.

APB Task Force Feedback on the National Strategy Priorities

The Priority Areas were:

1. improving understanding and acceptance of autism within society;
2. improving autistic children and young people's access to education, and supporting positive transitions into adulthood;
3. supporting more autistic people into employment;
4. tackling health and care inequalities for autistic people;
5. building the right support in the community; and
6. improving support within the criminal and youth justice system.

We added a seventh to this list:

7. safeguarding all ages of autistic people.

The five year strategy has three enables for Year 1 – 2021-2022:

1. improving research, innovation and examples of best practice;
2. improved data collection and reporting to drive system improvement; and
3. strengthened governance, leadership and accountability.

It added a recommended next step for council as follows:

Review the membership of the APB so that it reflects all age groups and covers all aspects of the lives of autistic people.

We asked the task force what the council should put as the top priority and the order of the rest of the priorities and our extra one of safeguarding. Not everyone responded and there was difficulty in understanding due to various reasons as follows:

- a) not having personal experience in certain areas;
- b) the age group covered was limited to adults for those who responded; and
- c) all of the priorities and our added one were all deemed as virtually of equal importance.

Overall Priority 5 – Building the Right Support In the Community came out as being the most important. This was for a number of reasons:

- a) by having the right support available would have a positive ripple effect outwards affecting all of the other priorities;
- b) this would also mean that Priority 1 would be tackled simultaneously – even if not covering all of the specifics of Priority 1;
- c) mental health is a critical problem for 60% of autistic people so having the right support in place would reduce the need for hospital admittance and generally improve all aspects of health, and would help achieve some of Priority 4.
- d) It was felt that there was a specific lack of effective support in the county to help autistic people mix with society as a whole.

It was, therefore, not surprising that Priority 1 came in as a close second. Healthwatch has already worked on Reasonable Adjustments which has been put on the council Talk Community website. This is an important part of this priority but there were misgivings in that how do we get people to actually access this website? One idea was that a leaflet could be distributed to every household, maybe with the next council increases notification, or in the magazine "Hereford Matters", as this ought to cover nearly 100% of residents. By concentrating on this priority it would impact and help towards achieving Priority 6.

We had already agreed that training and awareness for council staff who come into contact with all autistic people should be a priority. This would help us achieve Priority 4.

Working with the CCG would automatically help us achieve some of the priorities as you cannot separate aspects of an autistic person into healthcare, education, and so on. We need to deal with the whole person. Sharing data has been agreed but some national issues have come up meaning that the roll out did not start in September as proposed. The CCG are employing an Autism Champion and both the Chairs of the APBs in Herefordshire and Worcestershire have assisted in this work. Herefordshire Council and Worcestershire Council are now a part of the governance for the Intergrated Care Service (ICS) which is a big step and should assist in getting good outcomes for autistic people. Herefordshire APB was instrumental in getting an Herefordshire Diagnostic System in place, even though Covid has caused roll-out problems of this service. As part of the Governance Board we are able to ensure that priority 4 is pushed forwards.



Suicide Prevention Programme Herefordshire & Worcestershire ICS

(Wave 3 Funding, NHS England)

Lead:
Louise McEvoy

Community Development Workers:
Mark Billau, Caroline Kingston

Key Workstreams



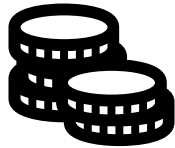
Awareness raising /
stigma busting campaign



'Middle-Aged' Men



Targeted work with those
in 'high-risk' occupations



Offering community
funding pots



Suicide safer communities
through training



Carrying out targeted engagement
work in relevant 'male' settings

Autism Community Priorities for Suicide Prevention

An International Society for Autism Research Policy Brief

February 1, 2021



Suicide in autism is a **hidden crisis**, overlooked by policy makers, clinicians and researchers worldwide. Population-wide studies in the US, Sweden and Taiwan show that autistic people are up to **seven times more likely to die by suicide**^{1,2} and **six times more likely to attempt suicide** than the general population.³ The risk of death by suicide is even greater for autistic people without intellectual disability.¹ It is also greater among autistic women, who are **13 times more likely** than non-autistic women **to die by suicide**.¹

- suicide is now the leading cause of early death in adults with autism and no learning disability
- adults with autism and no additional learning disability are over 9 times more likely (relative to a general population) to take their own life
- Multiple studies suggest that between 30% and 50% of autistic people have considered suicide



“Loneliness, feeling burdensome to others, social and communication difficulties, lack of support and trying to fit in by camouflaging autistic behaviors are some of the factors that increase suicide risk for autistic people”

“There is a lack of confidence and expertise in mental health providers supporting autistic clients, particularly those who feel suicidal.”

“Autistic people and those who support them report being excluded from services, not being believed by professionals, and receiving assessments and interventions that have been designed for other groups and therefore are inappropriate for their unique needs”

PRIORITY RECOMMENDATIONS: WHAT YOU CAN DO RIGHT NOW

Removing barriers to mental health services is the most important issue that autistic people and those who support them have identified. We can help remove these barriers by:

- **Explicitly identifying autistic people** and those with elevated autistic traits as high-risk groups in suicide prevention policy and clinical guidelines;
- **Developing research and clinical partnerships** with autistic people and those who support them to ensure that future training, intervention and prevention strategies are appropriate;

ADDITIONAL RECOMMENDATIONS

Autistic people and those who support them identified a number of issues and recommended numerous ways to improve their experiences of assessment and treatment:

- 1 **Believe** the autistic person who tells you that they feel suicidal, even if such information comes in a different or unexpected manner.
- 2 **Listen** to what the autistic person is saying.
- 3 **Ask** specific and clear questions. Autistic people can have difficulty identifying and describing their feelings, understanding metaphor or reading between the lines.

Table 1 - data required and proposed ongoing KPI's for Autism Adult diagnostic pathway

Questions	Month - <i>(fill in date here)</i>	Herefordshire	Worcestershire	Total
1	Number of new referrals in month			
2	Number of male referrals in month			
3	Number of female referrals in month			
4	Number of first contacts in month (acknowledgement of referral to individual)			
5	Number of initial assessments carried out in month			
6	Number of screened out referrals in month (don't get to stage 2)			
7	Wait time for first contact from referral - current average			
8	Wait time for initial assessment from referral - current average			
9	Total number of assessments waiting to start (backlog)			
10	Total number of ADOS stage 2 assessments completed in month			
11	Total number of people awaiting outcome following stage 2			
12	Referral numbers via PCN (GP locations)			

PNC Primary Care Network
 ADOS Autism Diagnostic Observation Schedule

Table 2 - One off information requested to inform strategy and priorities

2a - Legacy referrals		Centre to which the referrals were made						
Question	Item	Bristol	Gloucs	Worcs	Can gender profiles be supplied? If yes please attach.	Can the age profiles be supplied? If yes please attach.	Total	Notes
1	Number of legacy referrals inherited by family psychology service from previous services							
1.1	Of Q1. How many were not yet started							
1.2	Of Q1. How many were partailly completed							
2	What happened to people who were part way through their assessment when the contract changed? Were they restarted or completed by the original service? (Text response).							

2b - Current performance for processing legacy referrals	
3	How many full Herefordshire diagnostic assessments have been completed since the start of contract?
4	How many full Worcestershire diagnostic assessments have been completed since the start of contract?
5	What's the average price of a full assessment (spend to date divided by answer to Table 2, Q3 and Q4)
6	What's the cost of clearing the backlog (Table 1 Q9 multiplied by Table 2 Q5)

Table 3 - data required and proposed ongoing KPI's for Autism Children's diagnostic pathway

Questions	Month - <i>(fill in date here)</i>	Herefordshire	Worcestershire	Total
1	Number of new referrals in month			
2	Number of male referals in month			
3	Number of female referrals in month			
4	Number of first contacts in month (acknowledgement of referral to individual)			
5	Number of initial assessments carried out in month			
6	Number of screened out referrals in month (don't get to stage 2)			
7	Wait time for first contact from referral - current average			
8	Wait time for initial assessment from referal - current average			
9	Total number of assessments waiting to start (backlog)			
10	Total number of ADOS stage 2 assessments completed in month			
11	Total number of people awaiting outcome following stage 2			
12	How many familes were referred for a Carer's Assessment as a result of going through the diagnostic pathway			
13	Referral numbers via PCN (GP locations)			

PNC Primary Care Network
 ADOS Autism Diagnostic Observation Schedule