

**East Riding of Yorkshire
Autism Partnership Board
22nd May 2024 1pm-4pm**



People who came to the meeting:

Rani Rooke

Angel Forsyth

Patricia (Trish LeGrove)

Cara Petch

Michelle field

Janet Smith

Susan (Sue) Wardill

Susannah Trotter

Symone (Sym) Tomlinson

PC James Stothard

Rebecca (Rebz)

Nicki Sparling

Adrian Barnes-White

Carol A Ryan

Paul Clapworthy

Emma Borg

Ankar Mehrotra

Hannah Brown

Kath Trotter

People who could not come to the meeting:



Liane Kirk

Peter Measures

Natalie Sweeting

Tom Denham

Jenny Measures

Kevin (Kev) Wright

Elaine Holtby

Adele Rose

Hayley Grant

Emma Lillico

James McDonald

Rachel Benton



Meeting Agenda

Previous Minutes

We agreed on what was said in the last meeting on 3 April 2024.

We also updated the list of things to do (see the attached file).

Update from Autism Voice

Angel asked the group members about the Strategy and who should join the meetings. They suggested people from education, housing, transport, benefits and leisure. They also said that the strategy should be clear, show real stories, and inspire. It must have goals and targets for the next 5 years. Our plan should be lively and speak for autistic people and families. The members want the meeting notes to be easy to read with pictures, like the Learning Disability Partnership Board minutes.

Co-Chair

Rani said it's important to have a co-chair with real-life experience for the meetings. People are unsure about the role but want to try it, know the tasks and get training. We will need to talk about payments with the service team. This job is usually not paid. It is a volunteer job. **ACTION – Rani to follow up**

Sym volunteered because she has lived experience. **ACTION – Rani and Angel to follow up**

Michelle Feedback

Michelle gave feedback on autism assessments. There are 838 children waiting, with 137 waiting over a year. In East Riding, adults wait about six months. Michelle said there is a plan for children's waiting times. They will test it in schools. Schools

Waiting List



should see what they can do to help, like making small changes, until the assessment is done.

The plan says you can choose. At 40 weeks, you should know this. Providers give part of the help. A website is being made to show how to get advice, support, and resources.

We are looking at how to help children who need more care, like looked after children (LAC)



ADHD

We want to make a plan to help people with ADHD. We are thinking of ways to support them without just giving medicine.



Why is there an increase in children's referrals?

There are many people needing help. They had money before, so they had enough staff to help quickly. Now, with no extra money, the waiting list is longer.

Some people think they need a diagnosis to get help. But for children needing an Education and Health Care Plan (EHCP) at school, they can get support without a diagnosis. **ACTION – Michelle/Rani**

We need to look at a plan to support children aged 14 and older moving to adult services. **ACTION – Cara/Michelle**

Missed diagnosis

It is best to find out in childhood, but many adults still need to haven't had an assessment. This may be because parents or schools didn't see it or want it. We are now more experienced and better at recognising it. **ACTION – DASHBOARD on to next agenda for discussion**



School policy

We talked about how school rules (policies) fits into diagnosis. Many behaviour rules do not think about children who are neurodivergent. **ACTION – to speak with Childrens Education**



Strategy

We need the new Autism Strategy to be short and easy to read. We split into groups to see what we needed for our life plan.

To be part of the community?

People need the right help to join in with the community. Changes like bobble drop kerbs help us feel safe. We need chances to mix with everyone, not just special educational groups (SEN), we need them to be inclusive. Support from friends, travel training, and feeling accepted are important. Schools should give more help like work experience and career advice. Young people with autism need the right choices. Can home schoolers get support too?



To be Healthy

People need easy GP visits, help with emotions, and help from counsellors who have knowledge about Autism. We need fitting therapies, services that understand us, and respect for culture. We want to be happy, join groups, and understand and learn resilience.



Resilience – things to help us cope

We need to know ourselves. We want to feel free and independent. We need good friendships that help us. Be kind and respectful – don't talk down to me! Treat me how you want to be treated.



Health

I want joint reviews, so I only need to tell my story once. This is important and preferred.

What type of listening?

We need advice or someone to talk to.



We need to think of other areas too

Staff need to know the right ways to help. They should use clear words in care plans. Plans must be clear. Words can be



different for each family. We must understand and respect these differences.

How can we make people aware?

Always be autism friendly, not just for 'Autism friendly hours' but all the time.



We then talked about our new strategy and what we want in year 1

Awareness / individually / support

We need to include young people from age 14 in our groups. They can join TYLER group until they are 18, then move to speak up groups. We want everyone to have a say and feel included.



Support is important. We need to know what kind of help is useful. Parents and carers need better services. We also need good training like the Oliver McGowan training to share our feelings and experiences. **ACTION Trish / James – Police**



New members need clear information about our groups. We should have leaflets to explain what we do. Membership must be right for everyone. We also need autism communication passports and reasonable adjustments **ACTION – to share / discuss** Words and terms for the group (terms of reference) should be easy to understand. **ACTION - Rani**



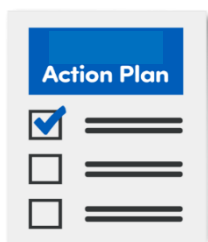
In Year 2

What happens after someone with autism leaves prison? What help do they get?

KIDS report to share **ACTION**

If something was not agreed in the first year, you can challenge it.

Check the first year. What actions were taken? Were there any changes? Can it keep going? Is more money needed?



This new strategy needs to be dynamic!

ACTION for Speak up group – if they are on a desert island, creating a new community, what do they want on their island?

ACTION Work Experience Feedback – Sarah Fletcher / Susannah Trotter, Reckitt's & St. Annes School, raise awareness and look at opportunities / internships? Look at the feedback in Hull for Media company and work environments.



ACTION – Rebecca, to share her information about the HOPPER bus and using it to travel to work. Employers are they disability confident or aware?

ACTION – put relaunch on Ageda for next meeting.

ACTION – name cards on the table when we meet (Trish)

ACTION -1-page profiles to be completed for key members / if desired.

ACTION -bring flipchart / pens / fidget toys / profiles, to meetings Trish / Angel

Action Tracker

We talked about making a plan called an 'Action Tracker'. This helps us see what we need to do, who is checking it, any feedback, and when it's done. ACTION – Rani to share with meeting notes

ACTION – could the tracker be colour coded to match the colours in each area of the Autism Strategy?

Meeting Location

ACTION – lived experience /& Angel to visit and feedback about suitable venues for the meetings.

Themes

We spoke more about the strategy and how we could theme the board meetings around each area or key theme. NHS Humber have a strategy that looks at; Understands, Accepts and Supports. The Humber Legislation is reviewed every year by Michelle. ACTION – send out Local Authority Strategy / Humber Strategy and plan of what to achieve.

ACTION - share strategy with Autism Voice and Hannah Brown for the Parent and Carer forums.

Experts by Experience

Rani wants more experts by experience on the board. She also wants a co-chair who is an expert by experience to help her.

ACTION - We could have a Q&A session to show we are responsible to the experts by experience. We could hold these sessions and invite members.

Any Other Business

Autism Crisis Team

Michelle talked about Humber's unplanned services. These services are not yet funded. They are looking at what help is needed during a crisis. They checked Humber Mental Health services and gaps in the support. They have done this with experts by experience.

They made a team to help in-patient Mental Health units and home treatment teams. This will be a small team with a level of expertise in autism. They will help with suicide prevention, spend extra time with people in crisis, and have a specialist psychologist. They will make sure plans include family and clear communication. Rebs shared that during her crisis, she felt misunderstood and couldn't share information properly.

ACTION - Rebs has a form to share that has been used for people in crisis and will circulate this with the Autism Partnership Board and Action voice - an updated copy is to follow...

This is part of 'wider learning' and means multi-disciplinary meetings (MDT) meetings are more detailed at the start. In the CRISIS team, they now say their name when answering the phone, which is more helpful. Practices have changed!

ACTION - Michelle is going to send this report to Rebs for her comments and then she will look at funding.





Next Meeting:

When? – 17th July 2024 @ 1-4pm