

This document aims to collate most of the Autism Voice discussion points. It's using heading to help with further discussion about how these ideas and needs could be included in the Autism Strategy.

- Blue highlighted sections are ideas or processes that have been discussed during system conversations, with no self-advocates present.
- Pink highlighted text indicates where the discussion originally took place. It also indicates the end of one specific point. Many points will cover the same need or similar information. Use the pink highlighted tags at the end of sections or points to help determine individual points, ideas and needs.
- Sometimes I have used square brackets []. This is where I've added in words for clarity.
- The headings used in this document are based on discussions within the Autism Voice Group and Autism Partnership board. They don't necessarily match up exactly with headings proposed for the Autism Strategy
- The appendix to this document contains the minutes from each Autism Voice meeting showing the discussions topics within the context in which they originally occurred.
- Some Autism Voice meetings were not able to go ahead due to low attendance or staff absence. This may result in gaps in the meeting dates. Where possible updates given at Autism Partnership Board meetings have been used in place of minutes (some Autism Voice discussions occurred over email instead of during a video call or meeting, these discussions were relayed to the Board).
- "Employment" could be another potential heading, but there haven't been many discussions about this. A lot of employment related discussion could fall under "Autism Friendly East Riding". The distinction could be decided by the board
- "Education" has limited discussion reflected in these notes. This is because colleagues from Education and Children's Services haven't been able to regularly attend the board meetings to direct discussion around these topics.
- The board has recently changed to become "The East Riding Autism and ADHD Partnership Board". The notes here predate this change.

1. What outcomes have been achieved from the last strategy? What has yet to be achieved?
2. What joint funding arrangements can be explored to achieve the outstanding outcomes?
3. What elements, wording and templates can be reused from the previous strategy?
4. Can we make the new strategy more person centred – from their point of view rather than a system point of view?
5. How can we make the new strategy more concise?
6. How can we give the partnership board meaningful oversight and accountability of the strategy?
7. How can we co-design the strategy with autistic self-advocates with appropriate consideration of their time and energy?
8. Short term goals?
9. Long term goals?

Diagnosis

1. The importance of language – the process for diagnosis is based around deficits. “It would good to see this changed” [Autism Voice - 24.11.22](#)
2. Autistic individuals need the choice about whether to disclose their diagnosis (therefore workplaces need to offer accommodations as a default or diagnosis agnostic accommodations). [Autism Voice – 19.01.23](#)
3. “Autism is something you are”. Progress needs to come from a question/position of “What do you need? How can we help?”. [Autism Voice – 19.01.23](#)
4. Pre-diagnosis – a need for reliable information and other resources [Autism Voice – 07.09.23](#)
5. Post-diagnosis – What community support exists? Can alternate models of support be developed (alternate to what already exists regionally). Discussion of a post-diagnosis group, “almost like therapy, that you access for a limited time, 3 months after diagnosis, sharing experiences and common examples, peer support. Idea shared about rather than having to access all sessions sequentially in a fixed time frame, could a “voucher scheme” be used. Vouchers to access 6 sessions, as and when the individuals wishes. This might allow for more meaningful engagement as the individuals understanding and experience builds. [Autism Voice – 07.09.23](#)
6. Update from Autism Voice The group did not meet on Teams this month because they were busy with other things. Instead, they answered questions by email. They decided to ask Michelle about the autism and ADHD referrals service. · What are the total number of referrals since the last meeting (e.g. in past 2 months)? · Total number of referrals? · How many assessments have been done since our last meeting? · How many diagnoses have been given since our last meeting? · How many referrals are for post-diagnosis e.g. sleep? · How many ADHD referrals? [Autism Partnership Board minutes 17.07.2024](#)
7. Diagnosis – better post-diagnosis for adults. [Autism Partnership Board minutes - 17.07.2024](#)
8. Diagnostic Services – and young people transitioning into adult services, but there are less diagnostic services for adults. This represents a cliff edge. How might this be addressed? Also, the number of inpatient beds has been reduced, this is desirable if people can be supported in communities, this is great in theory but what is the additional community support that would be put in place. [Autism Voice – 10.05.2023](#)

Education/Parents/Young People

9. Education - Autism and Neurodiversity within schools training to be explored with the education psychologists and the inclusion practitioners.
Autism Voice – 10.05.2023
10. Education, 1:1 if required, Autism Aware / time to complete tasks / practical education eg gardening, catering, animal care... Autism Partnership
Board minutes - 17.07.2024

Mandatory neurodiversity training

APE model – Awareness, Practitioner, Expert:

- elearning as a minimum requirement for corporate partners (awareness)
 - longer in-depth session (Practitioner) as a development.
 - Training delivered with Experts by Experience (Expert)
11. Training needs to be with people with lived experience. “Deficit Model of disability isn’t helpful. Negative language doesn’t provide a safe space for Autistic people going forward.” Autism Voice - 24.11.22
 12. Basic Autism Awareness - It was mentioned that there needs to be more basic autism awareness, this could be done through some small myth busting activities as well as providing more information about training/webinars/conferences taking place. - Autism Voice – 03.10.22

Peer Support

13. ***Peer Support – Rani Rooke (Humber & North Yorkshire Health and Care Partnership) [this has been italicised to differentiate it from other points under the mental health heading the bullet points and additional detail has been copied from the Autism Voice minutes]***

Rani came to ask what good Peer Support might look like.

Rani said that anything developed or any ideas put forward would likely need joint funding (from National Health Services and other corporate partners (I.E. Local Authority) or grant funding) and would require a business case – [Late addition to the notes] Anything formally commissioned would need to go through the appropriate commissioning process

Rani wanted to foreground the importance of autistic people having their say.

Discussion around Pre-diagnosis support and post diagnosis support and that this support is time limited (it's not ongoing).

Discussion around the valuable conversations the autistic community have with other autistic people and that important basis of comparison, "Is this my autism? Or is it something else?"

Discussion around a need for a "what works and what doesn't work with current providers?" conversation. "Why shouldn't there be a range of providers?"

Discussion around need for any burgeoning ideas to be given time to develop and be built – reference made to Learning Disability Development fund: a pot of money available to help develop projects, overseen by a Learning Disability Partnership Board. Is there funding available for the East Riding Autism Partnership Board to operate a similar model?

Agreement that this clearly seems to be only the beginning of a longer discussion that needs to involve more autistic self-advocates. Autism Voice – 10.07.23

14. More Peer Support / Meetings / Pre-arranged meet areas – not just in Hull! Autism Partnership Board minutes 17.07.2024
15. To connect with others within the region as local groups are often difficult to [find [?]] Autism Voice – 01.02.2024

Autism friendly Mental Health support

16. The line between mental health and autism support services is worth looking at. Suggestion that this should be a discussion topic for a future Autism Voice meeting and that the discussion about experiences related to this will naturally uncover reasonable adjustments that would apply to Townend court and other services/professionals. Autism Voice - 24.11.22
17. Mental Health – an article on BBC/Apple news about an individual being restrained in the wrong way and the negative impact this can have on them. This seems to be a common occurrence for people with autism and how this can lead them to crisis. Peer Support Work grants [mentioned earlier] seemed to have a focus on mental health services applying for these grants to support their work. "It's not always about what the service doesn't know, sometimes it's about having individuals with lived experience delivering support." Autism Voice – 10.05.2023
18. Experience shared of the crossover between Autism and mental health and how services totally ignored the specific needs of the individual. Prior to engaging with services, a document detailing needs, experience and issues was written by the individual. This document had been shared with a doctor/academic specialising in this area. This doctor had offered an opinion that the document was very useful in approaching the issue at hand. The individual had come up with an answer and done the leg work in making clear the steps to achieve the desired outcome. "This is what is wrong with me, these are the reasons why, this is how I think we should take things forward.", despite this, the system and services did not engage with the document or the needs of the individual. How can this be avoided in the future? How can Services develop their trust and ability to work with Service Users? How can Services better recognise Service Users as Experts by Experience? Autism Voice – 10.05.2023

19. Recap of Neurodiversity Mental Health Chat [this has been italicised to differentiate it from other points under the mental health heading the bullet points and additional detail has been copied from the Autism Voice minutes]

Themed Mental Health chat that was mainly focused around Autism (based on attendance).

Late diagnosed self advocates, parents and professionals present

At the end of the meeting, attendees were asked to list the support and services they would like so see:

Trauma from not being heard/believed/listened to.

Trauma from being blamed

Trauma from being threatened – leads to isolation (haven't told anyone)

Trauma from being Judged

Trauma from stigma and Assumptions

Not knowing where to access support

Peer support wanted!!! (came up Autism Voices Group)

Innovations in Dementia is a model of interest – family/households need support too, from people who understand

Discriminatory language

What can you offer me that meets my needs?

Need to flex education and support to specific issues such as PDA, ARFID, Perinatal,

Need	No of votes
<i>Training for staff and families around what is helpful in terms of support</i>	2
<i>Recognition of Autism and Pregnancy</i>	1
<i>Support and understanding for PDA</i>	1
<i>Support for eating issues and autism</i>	1
<i>Training for GPs/Counsellors to assist pre and post diagnosis</i>	3
<i>Adult women and young women with Autism</i>	7
<i>Support pre and post diagnosis</i>	2
<i>Family and Partner support</i>	3
<i>Post diagnosis Peer support (face to face)</i>	2
<i>Academy to educate public and ambassadors to spread the message</i>	2
<i>Education system to provide support to Neurodiverse CYP</i>	1
<i>Co-produced services</i>	3

Experiences shared around mental health units and lack of familiarity with Pathological Demand Avoidance. Experiences shared around not being listened to by the system and made to feel like “you’re making it up”, especially from a parent’s perspective.

Question around Pathological Demand Avoidance

Question around Central Coherence Theory – offer from a self—advocate to share thoughts on this at next Autism Voice Meeting [Autism Voice – 10.07.23](#)

20. Suicide Prevention – Autism specific [support is needed] [Autism Partnership Board minutes - 17.07.2024](#)

Accessibility (including Transport)

[Pathway \(User journey\) review for all corporate partners – are they Autism Friendly? How?](#)

21. Conversation about social issues and anxieties of an individual. This can cause issues with potential employment. There doesn’t seem to be an open communication about what the employer or the work place can do to support autistic individuals. [Autism Voice – 19.01.23](#)
22. Professional Curiosity when engaging with communities and individual issues – systems and processes should value compassion equally to efficient service, rather than just trying to deal with the issue at hand without fully exploring all needs and potential impacts – example referenced of a recent Hull Daily Mail headline of an Autistic man who was denied an emergency loan and had to resort to eating dog food. [Autism Voice – 07.09.23](#)
23. Point raised about experiences of individuals and families (accessing any service and support) can result in time lost for people and their families. “There are limits on resources. But we don’t expect urgent pressing things, impacting all elements of a person’s life, to take 2 years (or more) to be progressed or resolved” [Autism Voice – 10.05.23](#)
24. Social Opportunities – not just public services, autism acceptance / information / training sessions [Autism Partnership Board minutes - 17.07.2024](#)
25. Sports Clubs / Shops / Cafes – not just for ‘autism’ hours [Autism Partnership Board minutes - 17.07.2024](#)
26. Cinema – Cinema sessions should be later in the day. Sensory sessions should be at different times, not just when it suits the cinema. [Autism Partnership Board minutes - 17.07.2024](#)
27. A real issue is about how reasonable adjustments are made to help neurodiverse people in our communities. This will be picked up as part of Inclusion by the Strategy. In the short term we talked about making a leaflet for businesses. [Autism Partnership Board minutes - 17.07.2024](#)

Police and Community Policing

- 28. Recap of Meeting with Humberside Police [this has been italicised to differentiate it from other points under the police and community – the bullet points and additional detail has been copied from the Autism Voice minutes]***

Humberside Police, Eryc, Self Advocate – Matthew’s Hub unable to attend but shared details of the training they provide to police.

Made explicit that the intention of the meeting wasn’t to overshadow commissioned services already in existence.

Agreed that there was still value in Humberside Police hearing from self-advocates and their experience, and for self-advocates to better understand the processes and protocols that Humberside Police work towards.

*Agreed to have a meeting inviting all interested self-advocates to discussed opportunity for shared conversation and learning **Autism Voice – 10.07.23***

29. Positive relationships with Humberside Police were recognised and their involvement with the Partnership Board. Conversation about the trauma about being arrested and being remanded was shared. Humberside Police Professionals have advised their willing to explore how they can improve their training and responses to initial interaction, arrest, remanding and their overall duty of care. **Autism Voice – 19.01.23**
30. News story about an autistic teenager who was groomed and involved in a whole range of offences – within East Riding this needs to prompt a conversation about what can be done in our area to prevent similar occurrences. **Autism Voice – 19.01.23**
31. Prison statistic = 20-25% are neurodiverse. We need to look at how we have continuity of care when they leave prison. **Autism Partnership Board minutes 17.07.2024**

Autism Friendly East Riding

32. Environments – There’s probably some work we could do around design and good practice. There was some work done the other year around assessment units for children and young people - "It's Not Rocket Science" which raised some interesting points about building design, layout and usage. **Autism Voice – 03.10.22**

33. Transport - Improving awareness and acceptance in the transport sector and the importance of transport generally. For many autistic people (and other disabled people) transport is the only way they can access services. [Autism Voice – 03.10.22](#)
34. Inclusive Language around Autism. It's often referred to as a deficit. What can we do to change this? [Autism Voice – 19.01.23](#)
35. "There's a stigma with autism." Conversation about sudden awareness of the stigma around autism. Experience shared of two undiagnosed friends, neither one wants to pursue a diagnosis as they are worried that it will effect their job or how people view them personally. There seems to be a negative connotation attached to autism. [Autism Voice – 19.01.23](#)
36. In reference to the Council meeting, an example of "living libraries" was shared. Positive examples of autism, positive stories do exist and can be put forward. Example given of global job, innovative organisation and digital platforms created, and how autism enable the individual to excel in this position (negative aspects also shared around being exploited in terms of salary). [Autism Voice – 19.01.23](#)
37. Example given around apple computers, innovations and lightbulbs all being the result of folks who had autism and how autism allows for radical innovation. [Autism Voice – 19.01.23](#)
38. Neurodiversity work within ERYC (in terms of recruitment and employment). [Autism Voice - 24.11.22](#)
39. Autistic Identity and Autistic safety, feeling secure and being your authentically autistic self [Autism Voice – 10.05.2023](#)
40. All of life (outside of essential services: health, police, education). [Autism Voice – 10.05.2023](#)
41. Information and Resources – where are the gaps? How do we get the information out there? [Autism Voice – 10.05.2023](#)
42. Use experiences to improve upon and shape services to protect people from growing up and not receiving the right support from those services available. 1 person quoted 'we can't change the past, but we can change the future'. [Autism Voice – 01.02.2024](#)
43. To stop people from being seen as statistics instead of looking at solutions [Autism Voice – 01.02.2024](#)
44. The group talked about what has been important to share, how people can be viewed differently and they look forward to making changes for the future. People still want to continue to be involved and that the co-produced approaches continue to be important. Talked about how to get more people involved and help them to get there. People in different circumstances might need different ways to be involved such as during the day, evening sessions or online. [Autism Partnership Board 07.02.2024 \[in lieu of Autism Voice minutes\]](#)

Partnership Board

45. Who's here and who needs to be here? Having more autistic people on the board. Can we make it a more action focused board? "This is what we've discussed. What is happening as a result of this?" [Autism Voice – 10.05.2023](#)
46. To allow a space which isn't professional heavy where people can openly speak about experiences. [Autism Voice – 01.02.2024](#)

47. UPDATE CORPORATE WEBSITE for partnership board - <https://www.eastriding.gov.uk/council/working-with-our-partners/adult-social-care/autism-partnership-board/>

48. Find ways of sharing workload for corporate members of the board. We need to add resilience to this format of working so that one person being on absent doesn't prevent notes from being typed up and shared or actions being left unaddressed

49. Angel provided questions for them about the Strategy and who they want to be involved / invited to meetings...They suggested: Current portfolio holders, Education, Housing, Transport, Leisure. They also said that they like the minutes to be easy read / pictorial like the Learning disability Partnership Board minutes. Autism Partnership Board 23.05.2024 [in lieu of Autism Voice minutes]

50. A small group of people met for the Autism Voice session. They talked about:

- Progression pathways – how issues are raised and acted upon.
- Funding and support – funding for projects and support managed in the same way as the Carers Funding Model
- Information and resources – looking at what information and resources are available in the community. The group shared ideas of what they would like to see
- Co-production – the group talked about how organisations work (NHS and experts by experience, fees & expenses policy). Peer challenge focus group. A de-brief about the peer challenge. A paper from this will be shared by Peter
- Mental health & autism – the group talked about things affecting their mental health
- Professional curiosity – on-going conversation about it being a lottery of support depending on who you get at the end of the phone. Peter will share the notes from the group with this Board.

Peter said that the Autism Voices group want to know that what they're sharing with the Board means something and it is acted on. Peter asked how can the Board make sure this happens? Autism Voice group was set up to give self-advocates more time to discuss the issues important to them. It is about people coming together to talk about issues. Because it isn't a constituted group, they haven't been able to access any funding. Tim Coulson talked about The Transforming Care Partnership which has regular funding offering up to £5k support for projects or events which directly benefit people with a learning disability and / or autism. Tim shared the link: <https://humbertcp.co.uk/ongoing-tcp-fundingopportunities-500-5000-3/> Autism Partnership Board 20.09.2024 [in lieu of Autism Voice minutes]

APPENDIX – Copies of full notes from Autism Voice Minutes

Autism Voice – 03.10.22

Autism Friendly East Riding

Environments – There’s probably some work we could do around design and good practice. There was some work done the other year around assessment units for children and young people - "It's Not Rocket Science" which raised some interesting points about building design, layout and usage.

Transport - Improving awareness and acceptance in the transport sector and the importance of transport generally. For many autistic people (and other disabled people) transport is the only way they can access services.

Basic Autism Awareness - It was mentioned that there needs to be more basic autism awareness, this could be done through some small myth busting activities as well as providing more information about training/webinars/conferences taking place.

Autism Voice - 24.11.22

Autism Friendly East Riding

Training needs to be with people with lived experience. “Deficit Model of disability isn’t helpful. Negative language doesn’t provide a safe space for Autistic people going forward.”

Neurodiversity work within ERYC (in terms of recruitment and employment).

The importance of language – the process for diagnosis is based around deficits. “It would good to see this changed”

The line between mental health and autism support services is worth looking at. Suggestion that this should be a discussion topic for a future Autism Voice meeting and that the discussion about experiences related to this will naturally uncover reasonable adjustments that would apply to Townend court and other services/professionals.

Autism Voice – 19.01.23

Inclusive Language around Autism. It's often referred to as a deficit. What can we do to change this?

Conversation about social issues and anxieties of an individual. This can cause issues with potential employment. There doesn't seem to be an open communication about what the employer or the work place can do to support autistic individuals.

"There's a stigma with autism." Conversation about sudden awareness of the stigma around autism. Experience shared of two undiagnosed friends, neither one wants to pursue a diagnosis as they are worried that it will effect their job or how people view them personally. There seems to be a negative connotation attached to autism.

"Autism is something you are". Progress needs to come from a question/position of "What do you need? How can we help?".

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Mental Health – an article on BBC/Apple news about an individual being restrained in the wrong way and the negative impact this can have on them. This seems to be a common occurrence for people with autism and how this can lead them to crisis. Peer Support Work grants [mentioned earlier] seemed to have a focus on mental health services applying for these grants to support their work. “It’s not always about what the service doesn’t know, sometimes it’s about having individuals with lived experience delivering support.”

Experience shared of the crossover between Autism and mental health and how services totally ignored the specific needs of the individual. Prior to engaging with services, a document detailing needs, experience and issues was written by the individual. This document had been shared with a doctor/academic specialising in this area. This doctor had offered an opinion that the document was very useful in approaching the issue at hand. The individual had come up with an answer and done the leg work in making clear the steps to achieve the desired outcome. “This is what is wrong with me, these are the reasons why, this is how I think we should take things forward.”, despite this, the system and services did not engage with the document or the needs of the individual. How can this be avoided in the future? How can Services develop their trust and ability to work with Service Users? How can Services better recognise Service Users as Experts by Experience?

Point raised about experiences of individuals and families (accessing any service and support) can result in time lost for people and their families. “There are limits on resources. But we don’t expect urgent pressing things, impacting all elements of a person’s life, to take 2 years (or more) to be progressed or resolved”

A list of topics raised in the recent Autism Partnership Board were shared with the group:

- Who’s here and who needs to be here?
- Information and Resources – where are the gaps? How do we get the information out there?
- Autistic Identity and Autistic safety, feeling secure and being your authentically autistic self
- Diagnostic Services – and young people transitioning into adult services, but there are less diagnostic services for adults. This represents a cliff edge. How might this be addressed? Also, the number of inpatient beds has been reduced, this is desirable if people can be supported in communities, this is great in theory but what is the additional community support that would be put in place.
- Suicide prevention

- Justice System
- Renewal of Autism strategy
- Having more autistic people on the board.
- All of life (outside of essential services: health, police, education).
- Transport
- Employment

Can we make it a more action focused board? “This is what we’ve discussed. What is happening as a result of this?”

Autism Voice – 10.07.23

Recap of Neurodiversity Mental Health Chat

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- Late diagnosed self advocates, parents and professionals present
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 - Not knowing where to access support

- Peer support wanted!!! (came up Autism Voices Group)
- Innovations in Dementia is a model of interest – family/households need support too, from people who understand
- Discriminatory language
- What can you offer me that meets my needs?
- Need to flex education and support to specific issues such as PDA, ARFID, Perinatal,

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Post diagnosis Peer support (face to face)	2
Academy to educate public and ambassadors to spread the message	2
Education system to provide support to Neurodiverse CYP	1
Co-produced services	3
Positive health model	1

- Experiences shared around mental health units and lack of familiarity with Pathological Demand Avoidance. Experiences shared around not being listened to by the system and made to feel like “you’re making it up”, especially from a parent’s perspective.
- Question around Pathological Demand Avoidance
- Question around Central Coherence Theory – offer from a self—advocate to share thoughts on this at next Autism Voice Meeting

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- Made explicit that the intention of the meeting wasn’t to overshadow commissioned services already in existence.
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Agreement that this clearly seems to be only the beginning of a longer discussion that needs to involve more autistic self-advocates.

Autism Voice – 07.09.23

Pre-diagnosis – a need for reliable information and other resources

Post-diagnosis – What community support exists? Can alternate models of support be developed (alternate to what already exists regionally). Discussion of a post-diagnosis group, “almost like therapy, that you access for a limited time, 3 months after diagnosis, sharing experiences and common examples, peer support. Idea shared about rather than having to access all sessions sequentially in a fixed time frame, could a “voucher scheme” be used. Vouchers to access 6 sessions, as and when the individuals wishes. This might allow for more meaningful engagement as the individuals understanding and experience builds.

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Rani's original outline for task and finish groups (potential headings for the autism strategy)

1. A home -place to live
 - a. Develop universal template for good ASD housing
 - b. Supported housing service spec
 - c. Residential services spec
2. Community
 - a. Accessible universal services
 - b. Support to access universal services
 - c. Complex support needs
3. What to during the day
 - a. Access to universal provision/services
 - b. Support to access universal provision/services
 - c. Specialist gainful activity
4. Being healthy body and mind
 - a. Access universal services
 - b. Support to access universal services
 - c. Specialist services/Support
5. Life changes
 - a. Universal support
 - b. Low level specialist support
 - c. Complex support
6. Be safe
 - a. Universal
 - b. Low level
 - c. Complex
7. Right support for carer
 - a. Universal support
 - b. Low/medium support
 - c. Complex support