



Meeting held on 18 July 2023 on Teams

	Actions
<p>Tom welcomed everyone, and attendees introduced themselves.</p> <p>Unfortunately, Lauren Bowler is unable to attend this meeting so will be added to the agenda for the next meeting.</p> <p>Notes of the last meeting / matters arising:</p> <p>Actions from the previous meeting:</p> <ul style="list-style-type: none"> • Matt Hardy to come to a future meeting to talk through his work on Transition – Added to reference group for December and partnership board in the New Year. • Justin Price to meet with Tom Moore and Jane Gupta and link with Matt Hardy with his work. • Action Liz and Howard to link in relation to forensic services. • Liz to ask Laura Saunders if the Autism Oxford report about mental health inpatient services can be shared – Update – this needs final sign off from Laura Saunders before it can be shared. Liz to follow up • Liz to contact Mark Nuti and Tim Oliver with regards to manifesto accessibility - Liz spoke to Mark Nuti - he is passionate about making documents more accessible and is happy to discuss taking this forward. Liz would like to take an autistic person with her, to be discussed outside of meeting. • Samantha to circulate the survey details to the group and on the Latest News webpages - this has been done and the Coalition have had loads of responses. • Rename the meeting to Adults Autism Partnership Board - this will be considered as part of the branding work that is going on for the whole strategy. Adults will be used in calendar invites. 	<p>Carried forward – TM</p> <p>Carried forward - LW</p> <p>LW</p> <p>LW</p>
<p>Reference Group Update</p> <p>Tom gave some background about the autism reference group which is a group of autistic adults linked to the Autism Strategy. Changes have been made to ensure that the group’s opinions and discussions feed into the Autism Partnership Board and beyond. An autistic Co-Chair, Haywood Drake, has been elected and he will be invited to attend the Autism Partnership Board in future. Items that come to the board will go to the Reference Group first so that their views can be brought here. This will be built into the agenda.</p> <p>All Age Autism Strategy, Health, and Social Care Work Stream Update</p> <p><i>The presentation was circulated with the pre meeting materials.</i></p>	

Peer navigators are now in place in the Surrey and Borders Neurodevelopmental Team.

An analysis has been done to find what workforce would be required to meet the demand for referrals. This would cost a lot more than is available. There is now work going on with children's services to look at improvements to the all-age system within available finances.

The evidence from the Autism Oxford work, Healthwatch and Compassion in Crisis forms a picture of what diagnostic services and mental health support are like for autistic people. Liz thinks that this will provide enough evidence to re-start work in mental health service development for autistic people.

The Health Inequalities board for people with learning disabilities and autistic people has started however autistic people have asked for a separate board. Liz is looking at this after the summer and asked for help with governance arrangements.

Sara said that a joint autism inequalities board for adults and children would be good. There is a major issue when someone turns 18. Pip agreed.

Liz reported that the forensics work is underway, people are being discharged from hospital and the key working team is coming together.

Work pending

Autism health checks are being piloted in the North and we are waiting for results. The checks will probably go live Nationally in 2025 and Liz has been asked to look at system readiness in Surrey. This includes working with a group of GPs, and this work is just starting.

A group of autistic GPs have put together some very good training for GPs, Liz will share this.

She is still trying to secure funding for cardiovascular disease research.

Liz said that she went to a meeting yesterday about domestic violence against women and girls where people were very keen to have autistic women and girls represented.

Bex said that having social difficulties can leave people open to being manipulated.

Jane suggested that Liz contact jo@appeer.org.uk regarding the vulnerability of autistic girls.

The Reference Group raised a question about how non-diagnosed autistic people are being identified in mental health inpatient services.

LW

<p>Staff need to understand autism so they can make reasonable adjustments, whether people are diagnosed or not. It is important to be aware that neurodivergence is an issue when screening for mental health. There was discussion about other conditions such as POTS and Ehlers Danlos syndrome. Liz suggested that this is taken to the autism health inequalities board. Bex said that Ehlers-Danlos Society are a good organisation who she feels it would be worth joining up with, Liz made a note of this.</p>	
<p>LeDeR – Learning from the lives and deaths of people with learning disabilities and autistic people</p> <p><i>The presentation was circulated with the pre meeting materials.</i> Lynne Ramnanansingh presented This is a national service improvement program run locally at Surrey Heartlands. It was originally set up for people with a learning disability but from June 2021 also includes autistic people who don't have a learning disability. The program looks at what works well and what could be better, and identifies health inequalities.</p> <p>Lynne said she would like to be part of the Autism Health Inequalities board that Liz is setting up so that findings from LeDeR could be included. Liz to include her.</p> <p>Pain assessment tools - Bex said that it can be very difficult for autistic people to communicate what is going on with their body. Communication is a big thing, especially for people who are non-verbal. Lynne agreed and said that hospitals and GPs need to think about this. There are some good tools available that can be used.</p> <p>There is a program for women with learning disabilities and autistic women to try and improve uptake of cervical screening.</p> <p>Lynne said they want providers to have their own action plans and take responsibility for their own learning too.</p> <p>Tom talked about the importance of flagging so that hospital staff know that a person is autistic.</p> <p>Bex said that although data collection can seem arduous, there is a whole community of autistic people to be included. It's important not to forget non-verbal autistic people.</p> <p>Lynne is looking for someone to get involved in the screening work and is keen to talk about engagement. To come to next reference group.</p> <p>Wendy asked what a nurse liaison service for autistic people would look like, particularly in primary care.</p>	<p style="text-align: center;">LW</p> <p style="text-align: center;">LR</p>

<p>Lynne said the nurses help people to access health services and would be notified when people are coming into hospital so they can work wards to make reasonable adjustments and meet people's needs. They also deliver training for hospital staff. Liz said that for primary health care the nurses can support with annual health checks and can be contacted to support GPs to make reasonable adjustments.</p> <p>Lynne has asked that the review of the liaison service includes considering including autistic people and children. Royal Surrey has an autism liaison nurse but not all hospitals do. Liz has asked for this information from hospitals so she can highlight any inequalities but does not yet have a response from all of them.</p> <p>Bex said there is a balance between support and taking over. Options and flexibility are important. Lynne mentioned Oliver McGowan training, Liz said she could update on this in another meeting.</p>	<p>LW</p>
<p>Value of Diagnosis Research – HealthWatch Surrey</p> <p><i>The presentation was circulated with the pre meeting materials.</i></p> <p>Adam said the report is mostly focused on children and young people but hopefully still relevant. Tom said that the work is very relevant to this board as there are challenges about delivering diagnostic services across the board. People need to be heard so that future plans reflect what is important to people.</p> <p>Bex said that although there was discussion about self-diagnosis, often a formal diagnosis was needed to make changes in school. This is important for parents too as it is an intense strain for them as well. Bex said she was not diagnosed until she was an adult. There is a lot of misinformation online, perhaps there needs to be a safe resource for adults to use.</p> <p>Adam said we can learn from people's journeys when they are diagnosed as adults. When would diagnosis have helped? When could it have been picked up? The conversation needs to continue, and schools should be involved.</p> <p>Some people had paid for a private diagnosis but there were difficulties around what is required for the diagnosis to be accepted by services.</p> <p>Bex said that people need to be able to say what works for them and have this taken into the school setting. She acknowledged it was difficult for things to be individualised, but they need to find a way.</p>	

<p>Adam agreed that resources are needed to enable people to do what they need to do.</p> <p>Adam said he felt this was similar to hospitals in that lots of people and systems need to change. Some are better than others, need to look are where things are working well.</p> <p>Tom gave feedback from the reference group:</p> <p>A lot of parents find out they are autistic when children are diagnosed. Perhaps parents should be offered screening? The group emphasised the importance of keeping the autistic person at the centre of research like the Healthwatch project.</p> <p>Wendy said that we are all talking about the benefits for children and young people being able to access support. As an adult being diagnosed her experience was that there is no support.</p> <p>Adam said he would like to encourage the expansion of the groups to include adults.</p> <p>Sabrina said that she is hoping the new web pages she is developing on the Surrey County Council website will include reliable information to help people.</p>	
<p>Any Other Business</p> <p>Anna Attah will be added to the agenda to come and update about the Autism Friendly Communities work that she is doing.</p> <p>Jane and Tom agreed to discuss how the work Jane is doing with schools will impact on young people in transition, and how to share that with this Board.</p> <p>Bex said she felt that the experiences that adults had previously had when they were in school may be relevant and helpful.</p> <p>Sabrina suggested that the adult reference group may like to hear from Jane.</p> <p>Bex said there was a need to recognise that non-verbal autistic people who do not have a learning difficulty are being overlooked. She said these people are often assumed to have a learning disability when they didn't because of the difficulties communicating.</p> <p>Tom wondered whether any provider organisation who is supporting a non-verbal autistic people would like to get involved in the work of this Board. All Board members to think whether anyone in their networks might be able to get involved in this and make contact if so.</p>	<p style="text-align: center;">AA</p> <p style="text-align: center;">JG / TM</p> <p style="text-align: center;">All</p>

- Adam Connelly (presenting) – Surrey Health Watch
- Peter Self – Surrey and Borders Partnership Neurodiversity service
- Parvin Ahmed – Mary Frances Trust
- Leanda Hargreaves
- Harmandeep Admane – Surrey County Council Public Health

Summary of Actions

Action	Who?	Outcome
Justin Price to meet with Tom Moore and Jane Gupta and link with Matt Hardy with his work.	JP/JG/TM/MH	Tom will link in with Matt and others before he comes to the autism meetings.
Action Liz and Howard to link in relation to forensic services.	LW/ HC	To carry forward
Liz to ask Laura Saunders if the Autism Oxford report about mental health inpatient services can be shared.	LW	Needs final sign off from Laura before it can be released, Liz is following up.
Liz to contact Mark Nuti and Tim Oliver with regards to manifesto accessibility	LW	Liz spoke to Mark Nuti - he is passionate about making documents more accessible and is happy to discuss taking this forward. Liz would like to take an autistic person with her, to be discussed outside of meeting.
Liz to share training that was developed by autistic GPs for GPs	LW	Done
Lynne Ramnanansingh to attend reference group	LR	
Liz to update meeting on Oliver McGowan training in another meeting	LW	

<p>Anna Attah to update the meeting on Autism Friendly Communities</p>	<p>AA</p>	
<p>Jane and Tom will discuss sharing work on schools at the adult meeting, perhaps having some joint meetings</p>	<p>JG / TM</p>	
<p>Amanda / Tom to reach out to providers to see if there is a non-verbal autistic person who would like to get involved All to consider whether there are organisations supporting non-verbal autistic people that could help with this</p>	<p>AA / TM All</p>	