



Meeting held on 18 April 2024 on Teams

Introduction	Actions
<p>Tom welcomed people to the meeting, and everyone introduced themselves.</p> <p>Notes of the last meeting / matters arising: Actions from the previous meeting:</p> <ul style="list-style-type: none"> Liz to provide further update when plans for Health Inequalities Board come together. This is currently on hold as there is no capacity. Liz to speak to Amanda to arrange a slot to present the Downs Syndrome Act when is available- This is not available yet, this is to be carried over to next meeting. <p>Completed Actions</p> <ul style="list-style-type: none"> Sabrina to present ideas for the Website and to arrange with Amanda. Justin Price to meet with Tom Moore, Jane Gupta and Matt Hardy to discuss transition data and plans – This was done by email. Autism Oxford report about mental health inpatient services to be shared- will be sent to members of the group. Narmadha to send draft template for biography to board members for them to complete and send back- This has been actioned and awaiting responses from members to collate. 	<p></p> <p>LW</p> <p>LW</p> <p>SP/AA</p> <p>TM</p> <p>LW/LS</p> <p>NK</p>
<p><u>Wellbeing Project, Lynsey Way from Active Prospects</u></p> <p><i>The presentation was circulated with the pre meeting materials.</i></p> <p>Lynsey talked about the launch of a new Wellbeing Project specifically for autistic adults. This will be up and running at the start of June 2024. Active Prospects is a charity which operates in Surrey and West Sussex. They have a mix of accommodation-based support for people with different types of needs.</p> <p><u>Why are they doing a new wellbeing project?</u> Active Prospects did a survey asking autistic people they supported about the community mental health recovery service and their own support approaches. Lynsey shared feedback on this survey (<i>in slide pack</i>). This identified gaps in support, and led to a pilot project to focus on men’s mental health, with a wellbeing coaching programme.</p> <p>Bex asked why the pilot was centred around men’s mental health. He felt there needed to better understanding of autistic Assigned Female at Birth (AFAB) people</p>	

because a lot of them were getting lost in the system and being dismissed without emotional support because they are deemed overly sensitive.

Lynsey thanked Bex for sharing. She said that at first they got some funding specifically for men's mental health, and they knew a small group of autistic men who were not getting access to the resources that would help them. That project was just a pilot for a year and now they are expanding into a much bigger project that is more inclusive.

From April, they will be funded to provide 4 full time coaches and 2 social prescription coordinators (one of them with an outdoor focus). They are viewing this project as a 2-year membership. Members will be entitled to 12 coaching sessions. There is no timescale to the coaching sessions and the process can be very flexible. There are also group courses and activities on wellbeing topics throughout those two years. People will have personal wellbeing plans and a web app which will launch in June (This is open to anyone). They will be providing weekly check-ins to all members through text messages, calls or in person. They have an additional social prescription budget so they can do funded social prescriptions for at least 80 people. They are aiming for the project to reach 180 people in East Surrey. People can self-refer, or can be referred through a GP, CMHRS, College, University and Social Services.

Feedback from The Reference Group

The reference group generally liked this project and felt it would make a difference to people's lives. People in the group would have preferred that this programme covered the whole county but understood that this resource was not going to be possible within the funding allocated. As this was only a one-off project, members would really welcome something like this securing on-going funding.

Discussion

Bex asked how he can learn from this information. From his experience, he learns better on a hands-on approach. Information being talked about is not very easy for him to understand.

Lynsey said she is happy to have that discussion on a 1 to 1 basis. They do a lot of interactive experiential learning. They have been able to work with people to suit the programme to their own personal needs.

Sara said this was a great piece of work. She understands a lot of her members are going to ask why this programme is only covering East Surrey. She wanted to know where the border was and asked if the rest of Surrey would get access to the same scheme in the future.

Lynsey said they can offer this project free to autistic people because it is funded by the mental health investment fund, and they are only targeting East Surrey for this. Active Prospects would be happy to cover the West, however the funding is only for East Surrey. This includes Horley, Epsom and Ewell, Tandridge and Coulsdon.

<p>Viv said she was really interested in the project. She was wondering whether they speak to members about autistic burnout. This is Viv's specialist topic she provides training on.</p> <p>Lynsey said she would like to discuss this further with Viv, and that the project could tie in well with thinking about autistic burn out.</p> <p>Martin asked whether someone needed to have a diagnosis of autism or can people who self-identify also apply.</p> <p>Lynsey said they will be taking people that are self-diagnosed as well as those who have a diagnosis. They understand there are many people that are waiting for diagnosis but need support now.</p>	
<p>Break</p>	
<p><u>Community Mental Health Research– Wendy Smith from Surrey Coalition</u></p> <p>Wendy has lived experience of autism and of using mental health services. She spoke to us about her research looking at how suitable and accessible mental health support is in the community.</p> <p>Surrey Borders and Partnership was chosen to be part of the pilot scheme for community mental health transformation. Surrey Coalition was commissioned by the transformation programme to do some research aiming to understand:</p> <ul style="list-style-type: none"> • How suitable wellbeing services are. • What barriers people face when seeking and accessing support. • The experiences and needs of specific demographics – including neurodivergent people. • How the existing mental health support offer in Surrey and North-East Hampshire can be improved. <p>Surrey Coalition asked people's views through an online survey, and at the Autism Reference Group, the National Autistic Society and ATLAS (for young people). They organised focus groups on the topics raised and working groups with lived experience experts and system colleagues to refine the recommendations.</p> <p>Details of the findings and recommendations are in the presentation pack, and the full report is available on the Surrey Coalition Website.</p> <p>The Community Mental Health Transformation Programme will take the learning into account as they move forward with the programme. Budgets are very tight, which may limit the ability to implement some recommendations. However, they are optimistic that the mental health system will think creatively to find ways to implement the suggested changes.</p>	

Feedback from the Reference group

Some members very strongly recognised the term being ‘bounced’ between services. Overall, the feedback on the work was positive. People appreciated the information Wendy presented on appointments and accessibility, and the input into the community mental health transformation plans going forward.

Discussion

Wendy said they are running an all-day event in early May for system professionals at quite high levels. They will be running a workshop and sharing their findings, with the headline data and a link to the full report. They are hoping this will make an impact.

Shelley said it was a great piece of work and was interested to see how it is put into practice. The hospital has been looking at accessible information and gave an example of making sure that accessible language is being used in letters sent to people who use services.

Wendy agreed that people often found the use of jargon or complex language difficult.

In the chat, Bex said sensory input for cognitive behavioural therapy (CBT) is an important part for regulation. It is easy to go to therapy and identify problems, but helping him to understand how to fix those issues is another problem.

Wendy agreed - They have heard from a few individuals that when CBT has been specially adapted for them by a professional who really understood neurodivergence and tailored it to that person, it was helpful. But those people are in the minority. Other autistic people said CBT does not work for them or that it has done more harm than good.

Howard said the American Psychological Association (APA) services did a large-scale service review about autistic people accessing CBT. The results from that did not correlate to what Wendy’s report found, and different people may be affected differently. Overall, there evidence was that CBT can help autistic people but is probably not as effective as it is for neurotypical people.

[Pre and Post diagnosis support within Surrey and Borders \(SABP\) Neurodevelopmental Service- Howard Childs](#)

Howard spoke about the SABP pre and post diagnostic project which took place between December 2022-2023.

It is estimated that there are 34,000 autistic people in Surrey and 60% do not have a learning disability. Currently SABP have a 4-year waiting list for diagnosis with demand running approximately 3 times capacity. Their diagnostic rate is currently at 60%. The only post diagnostic support they provide are Recovery College courses.

The project had three aims:

- Screening and triaging to address whether people really needed the assessment.
- Pre diagnostic support looking at how to best support people on the waiting list.
- Post diagnostic support.

Details of the project are in the presentation pack.

Howard showed a workbook to help people understand how their autism diagnosis affects them personally.

Feedback from the reference group

The reference group felt the project was too short and wanted to know how this report was going to help in the future.

The group asked if the workbook can be shared for other people to use. Howard said there might be some difficulties trying to share this.

Action: Tom and Howard to discuss whether this can be shared.

Discussions

Olive asked whether there was any improvement or progress made on the 4-year waiting list.

Howard said there is hope and difficulties around this. The problem is that resources have not kept up with the demand. There is also a question of how quickly you complete an assessment versus how well you do the assessment. Tom added that this was not just a Surrey issue, long waiting lists are a nationwide problem. It is partly about being a victim of our own success in raising awareness of autism, so that more autistic people are recognised.

Howard highlighted the need to be careful about pre diagnostic support based around an autism diagnosis in case the diagnosis is not correct for that person.

Sara asked whether there was any prospects of keeping the pre and post diagnostic support open to people. Were they able to continue this with the funding. Howard said his manager is looking into this, but it is not guaranteed given the difficult financial situation for the public sector.

Tom said we need to try and do things differently, with increasing demand and shrinking resources. One thing that we have not always been good at is getting in early to help people.

Viv agreed with this and said too many autistic people are only discovered once they hit crisis.

Shelley said at Royal Surrey they have been pragmatic about flagging autistic people because of the long waiting list for a formal diagnosis. They have been flagging people who are waiting for a diagnosis with a suspected autism flag and giving them adjustments like hospital passports. The issue about this is that the reasonable adjustment flags would be attached to their record in the NHS spine. This information

TM/HC

<p>should not be on a person's record if it may not be correct. They have been doing it until now to support the reasonable adjustments, but not sure they will carry on.</p> <p>Sabrina asked whether she could find out more about reasonable adjustments flags on the NHS Spine. She said it was important to understand that the Equality Act does not require a diagnosis for reasonable adjustments. Sabrina said she has not been able to access a lot of services because reasonable adjustments had not been passed on from her GP through referral.</p> <p>Action: Shelley to feedback to Tom on who is leading at Surrey Heartlands on reasonable adjustments flag for the NHS Spine.</p>	<p>SC/TM</p>
<p><u>Any Other Business</u></p> <p>Wendy shared her experience attending the Oliver McGowan Mandatory trainers training as an autistic person with lived experience. She had her session recently at the Active Prospects headquarters. She said it was very well delivered and lots of reasonable adjustments, fidget toys were provided and lots of breaks. It was a very positive experience, and she recommends this to any autistic person who would like to be involved in delivering that training.</p> <p>Christina said there was some other good news about employment. Surrey Choices, Richmond Fellowship and Get Set will be working together under a new Work Wise contract to make sure there is employment support for people who are not eligible for it in other ways. It is open to people who have a mental health condition. They expect a big proportion of people who are referred to be neurodivergent. Christina to share publicity and information about the project as it becomes available</p> <p>Amanda said the Autism Oxford Report about hospital settings will be sent with the minutes (<i>detailed in slide pack</i>)</p> <p>Sabrina said that Surrey Coalition are now doing outreach to find young people who have Pathological Demand Avoidance. They are also looking for their families and those who want to be involved with writing a new position statement. If you would like to be involved with this, please email the allageautismstrategy@surreycc.gov.uk. More information can be found on the local offer web pages.</p>	<p>CE</p>
<p><u>Summary of Actions:</u></p> <ul style="list-style-type: none"> • Liz to provide further update once there is capacity to bring the Health Inequalities Board together. • Liz to speak to Amanda to arrange a slot to present the Downs Syndrome Act when available. • Tom and Howard to discuss whether workbook can be shared. • Shelley to feedback to Tom on who is leading at Surrey Heartlands on reasonable adjustments flag for the NHS Spine. 	<p>LW</p> <p>LW</p> <p>TM/HC</p> <p>SC</p>

Next Meeting:

Our next meeting is on Thursday 18 July 2024 at 10am to 12pm

Attendance:

Co-Chairs:

- Tom Moore – Senior Commissioning Manager Surrey County Council
- Bex Worgan

Board Members:

- Amanda Aldridge- Surrey County Council Engagement and Partnership Officer
- Haywood Drake
- Stephen Kicks
- Narmadha Kothandapani- Surrey County Council Engagement and Partnership Senior Business Support Assistant, Minute Taker
- Wendy Smith- Surrey Coalition
- Christina Earl- Surrey Choices
- Martin Woodward – Surrey Choices Employability and Autism Strategy Employment workstream co-chair
- Sabrina Peters – Surrey County Council Senior Communications Officer
- Viv Dawes- Autistic Advocate- advocate, author and trainer
- Kim Collen- Surrey County Council, All Age Autism Implementation
- Olive Aherne- Richmond Fellowship
- Jackie Vass- Surrey County Council, Occupational Therapist
- Alex Hird- Surrey Coalition
- Lynsey Way- Active Prospects
- Natalia Konieczka- Richmond Fellowship
- Shelley Cummings- Royal Surrey County Hospital
- Sara Truman- National Autistic Society
- Howard Childs- Surrey and Borders Partnership NHS Trust
- Paulina Trynda- Involve
- Joanna Grudzinska-Dmowska- The Grange
- Luke Simmons- Surrey and Borders Partnership NHS Trust
- Joy Bagshaw- Surrey and Borders Partnership NHS Trust

