



Surrey Autism
Partnership Board

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 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

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Viv said she was really interested in the project. She was wondering whether they speak to members about autistic burnout. This is provides training on.

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.

Martin asked whether someone needed to have a diagnosis of autism or can people who self-identify also apply.

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.

Break

Feedback from the Reference group

Some members 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.

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

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should not be if it may not be correct. They have been doing it until now to support the reasonable adjustments

Attendance:

Co-Chairs:

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