

Meeting held on 10 April 2025 on Teams

Introductions

Tom welcomed people to the meeting, and everyone introduced themselves. Tom noted that the agenda was busier than usual with more items to cover.

Actions from last meeting

- Update on when the Suicide Prevention Project is starting - Nanu has not yet provided an update on this. To review at next meeting
NK
- If members wanted to get involved in the Healthwatch work, please email disabilitycomms@surreycc.gov.uk

All

You Said We Did

Just before Christmas, the team working on the All-Age Autism Strategy released the "You Said, We Did" strategy update, which outlined progress to date, set goals for the next 18 months, and asked for feedback.

This was shared widely, and they received 28 responses from a mix of autistic individuals, parents, carers, and professionals – this was fewer than expected.

Kim emphasised some of the goals identified. These included:

- The progress made in delivering autism training to improve understanding will continue. Part of this will be expanding parenthood support and training for carers, as well as a new initiative aiming to improve diagnosis. We will also be building up delivery of the Oliver McGowan Mandatory Training, and exploring funding to expand the offer for autism specialist suicide prevention training.
- School autism-friendly reviews are expanding, working to improve resources for young people's future options.

- A Pathological Demand Avoidance (PDA) position statement is being developed looking at children with PDA, and should be ready by September. More engagement will be needed to relate this work to adult support.
- Health and social care priorities include pre- and post-diagnostic information and restructuring Surrey and Borders teams.
- Housing work faces challenges but continues to work with District and Borough Councils in Surrey to improve accessibility for autistic people.
- Employment efforts focus on increasing opportunities for autistic people, and supporting employers, with more detail later in this meeting.

The new implementation plan will run from April 2025, and will include continuous engagement and feedback, including through the Autism Partnership Boards, so that the final years of the strategy can continue to be driven by the views of autistic people and carers, and deliver as much change as possible.

Discussion

Sara asked if there is a document summarising the feedback received.

Kim responded that the feedback has not yet been widely shared and would need to be compiled so that it could be shared in a format that makes sense. - To bring this to the next Partnership Board.

Alex raised concerns about forthcoming PIP cuts and government policies on getting back to work, and their potential impact on employment support. She emphasised the need for accessible employers.

Tom agreed with the importance of working with employers to ensure accessible employment options. He also noted the link between work and burnout and mentioned that only 22% of autistic people are in employment, which is a sobering statistic.

10 Minute Break

Update on Co-production: Carers Breaks & Outcomes Framework

Jo provided an update on the Carers' Outcomes Framework discussed previously at the Autism Partnership Board. The framework has now been completed and is being implemented into grants and contracts. The presentation covered four main categories of outcomes:

1. Teamwork and Communication:

Carers should feel involved in decision-making and kept up to date.

Services must recognise carers as expert partners in care.

Professionals should check with carers to ensure they feel capable of providing care and understand their rights.

2. Knowledge:

Carers need clear information on where and who to go to for support.

Services should provide consistent and flexible information tailored to carers' needs.

3. Access to Services:

Carers want a one-stop shop for advice and information.

Services should ensure personalised support and agreed referral pathways to avoid carers repeating their stories.

4. Carer Health and Wellbeing:

Professionals should understand the pressures carers face.

Services should empower carers to thrive and provide equal opportunities, including flexible service hours for those in education or employment.

Discussion

Tom fed back from the reference group, highlighting practicalities of accessing carer support and changes in the process. The group had highlighted the importance of involving the person being cared for in understanding the carer's needs.

Tom also asked about the training requirements for carer services, regarding autism as well as accessibility more generally.

Jo explained that one of the services is Care Quality Commission (CQC) registered because it provides overnight breaks, but the rest are not. For

CQC registered services, Oliver McGowan training will be mandatory. Jo is working with providers to understand better what their training looks like and to encourage best practice. Jo noted that unless the Council have commissioned a provider to work with a specific client group, they can only suggest training rather than mandate it.

Kai highlighted that services often assume carers do not need support just because they are present. He emphasised the importance of meeting the communication needs of the person being cared for so they can contribute to conversations.

Colette shared her experience of professionals trying to exclude her from her adult son's appointments, despite his preference for her presence. She stressed the need for professionals to trust carers and understand their role in supporting the cared-for person.

Jo said that they are working on this issue, promoting good carer-friendly practice from our partner organisations.

Sara discussed the perception that carers are overprotective when involved in meetings. She highlighted the challenge of carers being seen as part of the problem rather than an essential support for the individual.

Jo explained about the service that supports carers who care for people with mental health issues, which includes educating hospital staff about best practices and carer-friendly approaches.

Wendy pointed out differences between mental health and physical health services in allowing carer involvement. She shared her experience of being excluded from appointments despite her need for support.

Jo said that her team are working to ensure that carers are recognised and supported in all settings.

Employment Workstream Update

Christina and Martin presented on the employment workstream of the All-Age Autism Strategy. They described work to increase job opportunities for autistic people, and to support those already in work to ensure sustainability. They have been part of a national pilot for supported internships, which has been successful in engaging young people and helping them find paid work.

Martin shared his personal experience of being diagnosed as autistic and finding employment through a supported scheme. He highlighted the gap between those eligible for adult social care support and those who are not and discussed work that has been done to bridge this gap, finding alternative funding sources for people not eligible for EHCPs or Adult Social Care. The workstream has also worked with employers to encourage the hiring of neurodivergent individuals and promoting initiatives like the Disability Confident scheme and the Autistic Index.

Christina said it was important to continue to provide a broad range of opportunities and maintain the quality of support. They aim to promote good news stories and ensure that employment support meets high standards. Martin discussed the transition to new government programs and the importance of matching people to suitable jobs and engaging employers to provide reasonable adjustments.

The presentation ended with a short video highlighting the success of a supported internship at the University of Surrey.

Discussion

Tom provided feedback from the reference group, who were pleased to see the work extending to people who were not eligible for other sources of funded support. The Reference Group also stressed the importance of understanding the impact of work on benefits.

Christine asked if they were working with organisations that have large numbers of volunteers, suggesting that volunteering could be a pathway to employment for neurodivergent individuals.

Christina confirmed that they do work with voluntary organisations and emphasised the importance of volunteering to learn skills and test one's ability to work.

Martin added that they have good relationships with organisations like Brooklands Museum, who take on many volunteers.

Alex raised a broader issue about the general understanding of disability, noting that many people only consider physical disabilities and may not understand the impact of invisible disabilities.

Christina agreed and mentioned the importance of raising awareness through real stories and videos to stop misconceptions. Martin added that raising awareness among employers is crucial and that some

employers have requested training around autism and autistic employees.

Tom added that training is offered to community settings, including employers, as part of the Autism Friendly Communities work.

Sara asked about circles of support, which seemed to have disappeared from the area. Tom said that circles of support is not a specific stand-alone project but is part of person-centred planning that organisations put in place when they see it as useful for someone they support.

Oliver McGowan Mandatory Training in Surrey- Update

The Oliver McGowan programme is mandated to deliver training to all health and social care staff. The training is divided into two tiers. Tier 1 consists of an e-learning course and an online seminar. This is for staff members who do not have direct contact with people with learning disabilities or autism. Tier 2 includes the e-learning and a full-day face to face training course. It is for all staff who support anyone with a learning disability or autism, or who make decisions that affect them.

Currently, four organisations are delivering the Oliver McGowan training in Surrey: The Care Talent Collective, The Good Consulting Company, Dynamic Training, and Autism Oxford.

To date, 2,500 people in Surrey have completed Tier 2 training, with 64% of participants being NHS staff. Tier 1 training is now also being offered in Surrey, with 40 experts with lived experience trained to deliver the programme. They are not recruiting any more experts at the moment, and by late summer, they aim to train 1,000 staff per month in Tier 2.

All acute hospitals in Surrey are fully engaged with the programme, and there has also been good uptake from Surrey and Borders. Despite some challenges in getting started, the feedback has been very positive, particularly from primary care, with some GPs stating it was the best training they had ever received.

Discussion

During the discussion, Wendy shared positive feedback from an associate director of nursing at the Royal Surrey Hospital, who said that

the Oliver McGowan training was the best study day he had attended in his 15 years of working.

Tom fed back that the reference group were very positive about the fact that the training was led by people with lived experience. There was some frustration with previous training that lacked this element. There were concerns about geographical coverage in the parts of Surrey covered by Frimley ICB rather than Surrey Heartlands. Camilla explained that while Surrey Heartlands was ahead in implementing the training, Frimley was also starting to make progress.

The Reference Group had raised that NHS services were still not fully accessible to them, and that progress to improve understanding in all services seems slow. Camilla agreed that it would take time but emphasised the positive movement generated by this training.

Wendy asked whether there was a possibility of introducing Tier 3 training. Camilla explained that while there were no concrete plans at the moment, they were investigating the possibility. She mentioned the need to balance the investment in Tier 3 training with other training needs and expressed her willingness to take direction from the group regarding priorities.

Kai shared his recent positive experiences with emergency services. He noticed a difference in their approach and understanding of meltdowns. Camilla was pleased to hear this and requested that Kai provide this feedback in writing to motivate the services to continue their positive direction.

Kai emphasised the importance of a calm approach during meltdowns and mentioned an infographic by Viv Dawes on how to help in such situations. Camilla and Tom agreed that this could be a useful resource to explore further. (*Update – Viv's resource on meltdowns is here* [Autistic Meltdowns \(Document \(A4\)\)](#))

Summary of Actions

- Update on when the Suicide Prevention Project is starting- Nanu has still not provided an update on this. To review at next meeting.
NK
- Share summary of feedback on last year's You Said We Did document
KC

Next meeting dates:

Thursday 17 July 2025 – 10am to 12pm

Attendees:

Co-Chairs:

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

Board Members:

- Narmadha Kothandapani- Surrey County Council Engagement and Partnership Senior Business Support Assistant, Minute Taker.
- Jane Gupta- All Age Autism Strategy, Surrey County Council
- Kim Collen- All Age Autism Strategy Manager, Surrey County Council
- Sara Truman- National Autistic Society
- Joy Bagshaw- Farnham Road Hospital
- Camilla Ford- NHS Surrey Heartlands
- Parvin Ahmed- Mary Frances Trust
- Christine Malik- National Autistic Society
- Vanessa Clark- All Age Autism Strategy
- Luke Simmons- Surrey Borders and Partnership Trust
- Christina Earl- Surrey Choices
- Martin Woodward- Surrey Choices Employability and Autism Strategy Employment workstream co-chair
- Wendy Smith
- Colette Lane- Surrey and Borders Partnership NHS Trust
- Sabrina Peters- Surrey County Council Senior Communications Officer

- Alex Hird – Surrey Coalition
- Dr Jill Rasmussen- PSI-NAPSE
- Jo Neville-Rye- Senior Commissioning Manager for the Carers Strategy, Surrey County Council