



## Meeting held on 19 October 2023 on Teams

<b>Tom's Introduction and Ground Rules:</b>	<b>Actions</b>
<p>Autistic members of the board have requested a check in and check out for each meeting to check whether everyone is ok. Non-autistic members are to join after 10mins at the start and end of the meeting.</p> <p>Last meeting the chat was very busy and some of the conversations that were happening in the chat were different from what was being discussed in the meeting. Some people found this overwhelming. From now on, if you are putting something in the chat, it should be relating to the topic under discussion and will be referred to during the meeting.</p>	
<p><b>Notes of the last meeting / matters arising:</b></p>	
<p>Actions from the previous meeting:</p>	
<ul style="list-style-type: none"> <li>Justin Price to meet with Tom Moore, Jane Gupta and Matt Hardy with his work - To roll over to next meeting.</li> </ul>	<p><b>Carried forward – TM</b></p>
<ul style="list-style-type: none"> <li>Action Liz and Howard to link in relation to forensic services - Complete - Liz and Howard have offered their support to future work.</li> </ul>	
<ul style="list-style-type: none"> <li>Autism Oxford report about mental health inpatient services to be shared – Laura to send presentation to Liz so this can be sent out.</li> </ul>	<p><b>LS/LW</b></p>
<ul style="list-style-type: none"> <li>Liz to contact Mark Nuti and Tim Oliver about manifesto accessibility - Liz spoke with Mark, and Liz and Bex will be meeting Mark and Sinead to discuss. If anyone else would like to attend, please let Liz Williams know.</li> </ul>	<p><b>LW</b></p>
<ul style="list-style-type: none"> <li>Liz to share training that was developed by autistic GPs for GPs- This can't be shared, as it is only accessible to health staff. It will be shared at the Autism health inequalities board first meeting. Liz is happy to attend one of the autism reference groups and bring a few clips of the training to the group to see what people thought. Liz said she is planning a health and inequalities boards for autistic people, aiming to start in November.</li> </ul>	<p><b>LW</b></p>
<ul style="list-style-type: none"> <li>Lynne Ramnanansingh to attend reference group- Meeting to be scheduled for Lynne to go through LeDer work.</li> </ul>	<p><b>LR</b></p>
<ul style="list-style-type: none"> <li>Liz to update meeting on Oliver McGowan training - Plan this for a future meeting when plans are further on.</li> </ul>	<p><b>LW</b></p>
<ul style="list-style-type: none"> <li>Anna Attah will update the meeting on her work on autism friendly communities- This is on the agenda today.</li> </ul>	<p><b>AA</b></p>
<ul style="list-style-type: none"> <li>Jane and Tom will discuss sharing work on schools at the adult meeting, perhaps having some joint meetings. This has been actioned. Aim to arrange an annual meeting, additional to the autism and partnership board meetings because we have full agendas for all the meetings.</li> </ul>	<p><b>TM / JG</b></p>
<ul style="list-style-type: none"> <li>Amanda / Tom to reach out to providers to see if there is a non-verbal autistic person who would like to get involved. Emailed 29/8. No one immediately coming forward for this, but people have said they will keep it in mind.</li> </ul>	<p><b>AAI/TM</b></p>

## Autism Friendly Communities: Anna Attah, including feedback from the Autism Reference Group. Presented by Tom

*The presentation was circulated with the pre meeting materials.*

Tom talked through Anna's slides about Autism Friendly Communities. They have been running a pilot of this work in Redhill, which is almost complete and are looking to roll it out across the county.

Why do we need to take action?

Most autistic adults are not accessing or are not eligible for statutory specialist services, so this is about working with communities to make them more autism accessible. Tom and Anna have been recruiting people around Surrey for this work.

The plan is for people to address barriers accessing all sorts of services and community locations such as

- GP's
- Housing
- Leisure centres
- Shops and Business

The pilot group in Redhill successfully bid for better care fund money. They organised two events which were quite different from each other, but both went well. One was an event in the library and theatre for local organisations and members of the public to attend. Local service providers had stalls and shared information to raise awareness of autism and publicise the work they were doing. The group funded development of materials to raise awareness with the public.

For the second event, materials were developed by autistic people with the tag line "Turn It Down for Autism" encouraging businesses to make things more accessible to autistic people. The group visited all the shops and businesses in Redhill with that information and had conversations with people. They had some very positive responses from businesses.

The Redhill group also funded development and delivery of co-produced training for community organisations including charities, voluntary sector partners and businesses. Over 80 people in the Redhill area took up the training, and feedback was very positive.

The project took a lot of time and work to put together. We don't have the resources to copy this project in each town (There are over 100 towns in Surrey). Instead, we are looking to use the community networks already in place through the ICB (Integrated Care Board). The NHS sub divides Surrey into areas called "Places". The five places we are looking at are: Guildford & Waverley, North West Surrey, Surrey Downs, East Surrey, Frimley Health and Care. This is still in early stages – we are recruiting people to form these groups.

East Surrey Group is the closest to getting started. We are using the existing Redhill group, and looking to recruit more partner organisations so that other

parts of East Surrey are covered. The next meeting for this is at the end of this month.

The second group will probably be in Guildford and Waverley because we have been able to make some good links there. The library is very engaged, there is a peer-run group for autistic adults that are keen to be involved, there is an existing "safe places" scheme who we are hoping will join, and we have good borough council links.

We will be looking to have a launch event in each area. The East Surrey one is likely to take place early next year, and for Guildford and Waverley we are aiming for April.

Rebecca put in the chat: For Surrey Heath and Farnham perspective, I have set up a meeting with our Frimley South LD and Mental health commissioning manager to discuss how we can roll this out. It would be good to understand how Guildford and Waverley will be working so we are aligned as we are neighbours.

We need autistic people to be centrally involved with this work to ensure the priorities are right. All encourage people from their networks to get involved. This could be anyone keen to develop autism friendly communities in a local area, particularly:

- Autistic people
- Family members
- Community leaders or people who are well-connected in their community
- Community organisations – charities, services, businesses
- Anyone who wants to bring energy and action to this work

Bex (in chat) said social media would be helpful to reach people and share information. Tom said it would, and we could do with some social media expertise in the groups.

Tom said he and Anna will feedback on this project as they go along.

### **Question and Thoughts**

Emma, Camberley Job Centre, Disability Employment Officer. Emma works at the Camberley job centre and would like them to be involved with the autism friendly communities.

**Action: Tom and Anna to contact Emma to discuss further**

Tom fed back the discussions at the reference group.

We discussed linking with the safe places scheme that is operating in some parts of Surrey and using their networks. Businesses or shops identify themselves as a safe place, they put a sticker in their window. If someone is having a bad time when they are out, the sticker shows them that this is a place someone will give them time and understanding and try and help them out. It would be useful for those safe places to be aware of autism and commit to being autism-friendly too.

**TM /  
AAt**

Training for community partners should include autism and mental health and how to avoid harm for autistic people in community settings.

We also discussed changes taking place for community support for autistic people who are not eligible for statutory services. Some of the services being offered in groups by the National Autistic Society have been reduced or combined, and some have gone online instead of being face-to-face. Tom said the Autism Strategy work is looking at other ways of supporting these groups currently in the community.

Liz asked in the chat. Tom can you connect me into the mental health training?  
**Action: Tom to discuss this with Liz**

**TM/LW**

**Community Opportunities Services: Marnie Cotterill and Thomas Moore including feedback from the Autism Reference Group.**

This section is about people who are eligible for funded social care services. Surrey County Council Adult Social Care funds over 100 organisations who provide support in the community of one kind or another. About half of this is provided by Surrey Choices, which is a local authority trading company. That means they are majority owned by the County Council. We want to make sure what is being delivered is aligned as much as possible to what people want, and to make sure that they are getting value for money.

Tom wants to hear what people would like to see from services.

Looking at what organisations are currently providing; this can be divided into four headings:

- Community Services - Traditional day centres or support in a building in the community and going out from the building.
- Outreach Support – Support staff meet someone at their home or in the community and support them to take part in community activities.
- Employment Support
  - Employment schemes (e.g., a charity shop or café set up for volunteering or work opportunities for disabled people).
  - Supported Employment – where people are supported in mainstream employment.
- Travel Training

People have already told us that they value:

- The opportunity to meet people
- Learning skills to be more independent
- Having choice and control
- Finding work and volunteering

Tom asked - What works and what could be better in these services?

Bex said there was a lot of focus outside of the home, where social care people come in and help people in their homes. It is all about going outside and there

needs to be a holistic approach with respect to social care. She said that she has a lot of support with things that need doing at home and this is because she needs help with maintaining her flat.

Liz spoke about opportunities and how they connect the social care offer into opportunities in the broader system. She spoke about the Oliver McGowan Mandatory Training, which will bring jobs for some autistic people as well as people with a learning disability in Surrey. We need to train 56,000 health and social care staff, so we will need a lot of trainers. We are working with Surrey Care Talent Collective as a group of providers, including Surrey Choices and Mike Leat (Autism by Experience), and are hoping they will be recruiting trainers.

Haywood asked whether there will be full time training roles?

Liz said they do not have the answer for this yet. Liz said that Christina will discuss with the Surrey Care Talent Collective and Oliver McGowan team.

Tom asked whether either opportunity is at the point yet where autistic people can put themselves forward. Liz said it was quite close, and we will get the information out through this network as soon as it is available.

Liz also mentioned a successful bid to the Department of Work and Pensions for 6.3 million pounds to support employment opportunities in Surrey. That bid includes some support for autistic people to get into employment.

Liz suggested to bring Rebecca Brooker to the meeting to discuss the £6.3 million 'individual placement scheme/service' in primary care and how it would apply for autistic people. Amanda to contact her to check availability.

Liz is doing some work to make sure that if you have a diagnosis of autism, it is on your GP register. This will mean better understanding of the needs of people across Surrey.

#### Feedback from the reference group:

The discussions at the reference group were focused on travel training and employment support.

One of the things people said needed to happen was training for employers to understand the positives as well as the challenges of hiring autistic people and how to make reasonable adjustments. Some people fed back some good examples of reasonable adjustments, while others raised downsides of employment, and risk of burnout.

For some people, reasonable adjustments need to include the option of reduced and flexible hours.

In terms of travel training people highlighted that it is often not a quick fix. For some people learning different routes can take time to pick up. Learning one route does not mean you should be considered independent when you need to go somewhere different.

AAI

<p>We also discussed access to public transport, and the importance of clear information and good communication from staff for autistic people.</p> <p>Christina shared some good news. Surrey Chambers of Commerce are holding a series of events for employers, about neurodiversity in the workplace. This is called 'Hidden Talent' and focuses on what adjustments employers can make for neurodivergent employees. This has been funded by better Care Fund through the All-Age Autism strategy.</p> <p>There is one coming up in Reigate, and then in January there's one in Surrey Heath. Anybody is welcome to attend. It is aimed for employers, and they are focused on people who have had successful employment journeys.</p> <p>There is some new adult travel training available through a pilot scheme funded by Surrey County Council and provided by Surrey Choices. If people are eligible for adult social care, they can ask to be referred onto it by their Social Worker. They have already started training some people and this can be tailored to people's needs.</p> <p>Emma Langdon, DWP: Very positive to hear about any kind of work programme and she said they would like to be more involved and bring more autistic people into the service.</p> <p>Tom suggested that Emma could be involved with the Autism Friendly Communities project but also recommended that she could speak to Christina who co-leads the Employment workstream for the All-Age autism strategy.</p> <p><b>Action- Tom to speak to Emma</b></p> <p>If anyone else has anymore thoughts on this discussion, please email <a href="mailto:ldcommunication@surreycc.gov.uk">ldcommunication@surreycc.gov.uk</a></p>	<p><b>TM / EL</b></p>
<p><b>Royal Surrey Hospital Autism Support - Shelley Cummings</b></p> <p><i>The presentation was circulated with the pre meeting materials.</i></p> <p>Shelley presented on behalf of Lauren Bowler who is the learning disability and autism specialist nurse at the Royal Surrey. The Royal Surrey have a full time Nurse, who supports autistic people as well as people with learning disabilities.</p> <p>All the acute trusts have learning disability liaison nurses. However, The Royal Surrey recognised that that there were a lot of autistic people without a learning disability, who also needed additional support and reasonable adjustments, and their needs were not being met. Since July last year the trust has employed somebody to support autistic people as well as people with learning disabilities.</p> <p>Lauren has worked at the Royal Surrey for many years, and she recognised the concerns she was receiving in referrals, including:</p> <ul style="list-style-type: none"> <li>• Lack of awareness of the needs of Autistic people when accessing healthcare</li> <li>• Reasonable adjustments were not being made</li> <li>• Lack of specialist support for autistic adults accessing the hospital</li> </ul>	

- Communication difficulties
- Hospital environment: Hospitals can be noisy and there is a lot of sensory overload for people who are autistic
- Monitoring the care they were providing. The hospital did not have records of individuals who are autistic, and so could not monitor how well their care was working.

The hospital now uses an electronic flag system. If an autistic patient wants it, they can have the flag added to their records to say they are autistic. By adding this flag to records they can:

- Establish and share information about that person's needs and what adjustments may help.
- Monitor complaints made.
- Analyse patterns of concerns if the hospital is not getting it right.

The hospital is working to educate staff about what reasonable adjustments can be made for a person. They have introduced an [autism passport](#) that an individual can give to people, which clarifies adjustments the person may need.

Lauren is now employed at the Royal Surrey full time (currently on maternity leave) so they are advertising for somebody to cover for her. In the interim, Shelley is covering her role a few days a week.

Currently, the Royal Surrey is the only trust, apart from St Helier that has a specialist autism nurse for adults. This is something that needs to be considered across the whole of Surrey. If someone requires support for an outpatient appointment, this is something they can help provide if they have been notified in advance.

If you have any further questions Shelley is contactable by phone on: 01483571122 (ext.3012), Email: [rsch.adultlearningdisabilitiesandautism@nhs.net](mailto:rsch.adultlearningdisabilitiesandautism@nhs.net) or [rsch.cyplearningdisabilitiesandautism@nhs.net](mailto:rsch.cyplearningdisabilitiesandautism@nhs.net) or Website on: - [www.royalsurrey.nhs.uk/the-learning-disabilities-and-autism-team](http://www.royalsurrey.nhs.uk/the-learning-disabilities-and-autism-team)

### Questions and Answers

Bex asked if it is possible to put preferred way to communicate on the passport. She has an app on her phone that if she types it in it will say things out loud because becoming non-speaking can happen to her in a stressful situation. Bex also thinks there needs to be awareness so that if someone has a meltdown, there are proper plans in place to help de-escalate rather than using a more heavy-handed approach.

Shelley said that responding to meltdowns is included in staff training. Making sure that people are aware that if somebody is getting agitated or they appear to be getting cross or they appear to be withdrawing from you, it may be because they're overwhelmed. It's not because they're aggressive, and they might just need a little time out from the situation.

Using the autism passport is very useful as it can tell staff what they need to do for you specifically. They are currently looking at trying to introduce a quiet room

within A&E that can help people calm down, including mood lighting. This can be useful for staff too.

Sabrina asked for a copy of the autism passport and asked whether it is based on existing passports that are available. The passport that they use is from the National Autistic Society: [My health passport \(autism.org.uk\)](https://www.autism.org.uk/healthcare/my-health-passport).

Shelley said this can be printed and brought into the hospital and uploaded to the system, so it is there for next time.

Sabrina asked Shelley if she has investigated an access passport or the access card. Having it all done on an app is a lot easier rather than having to send an e-mail or to print them off as sometimes the more steps that there are in communicating, the less likely that is to happen and can cause huge barriers.

**Action: Sabrina and Shelley to discuss the access card system.**

**SP / SC**



<p><b>Any Other Business</b></p> <p>Sabrina shared that a non-verbal person has been employed into project officer level role in the council now which is great news, and it has been really good to see how their workplace adjustments have been well communicated.</p> <p>Liz said that she now has the NHSI improvement Report from all the acute hospitals in Surrey and is busy analysing them. She will bring a slide pack to the autism reference group when this is complete.</p>	<p><b>LW</b></p>
<p><b>Future meeting dates:</b></p> <ul style="list-style-type: none"> <li>• Our meeting dates for next year are to be confirmed.</li> </ul>	

**Attendance:**

**Co-Chairs:**

- Tom Moore – Senior Commissioner Surrey County Council
- Bex Worgan



**Board Members:**

- Amanda Aldridge – Surrey County Council Engagement and Partnership Officer
- Narmadha Kothandapani- Minute Taker
- Shelley Cummings – Royal Surrey County Hospital
- Liz Williams - Joint Strategic Commissioning Convener- Learning Disability and Autism and all age Mental Health
- Christina Earl- Surrey Choices
- Martin Woodward – Surrey Choices Employability and Autism Strategy Employment workstream co-chair
- Sabrina Peters – Surrey County Council Senior Communications Officer
- Sara Truman – Surrey NAS
- Jane Gupta – Service Manager, Commissioning, Surrey County Council
- Harmandeep Admane – Surrey County Council Public Health
- Emma Langdon- DWP
- Christine Malik- NAS
- Tim Harrison- NHS
- Nicole Fayter- SCC, Project Manager for All Age Autism
- Mariam Watling- Surrey County Council

- Luke Simmons- NHS
- Rebecca Dalton- NHS Frimley ICB