**Sheffield Autism Partnership Board**

**24th February 2025**

**In Attendance:**

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| Anna Guest **(Chair)** | Siobhan Salter **(Minutes)** | Mary Vere |
| Chinyere Ehosiem | Michelle Cook | Jessica Beech |
| Rachel Hardy | Kelly Scargill | Helena Lath |
| David Newman | Sylvia Johnson | Joanne McCrum |
| Chloe Wilks | Rebecca Fletcher | Alexis Chappell |
| Charlotte Worthington | Katie Monette | Katie Drinkwater |
| Rebecca Batley | Joe Hamshere | Ben Duke |
| Helena Lath | Raheel Baig | Susan Kirkman |
| Christine Anderson | Ian Murphy |  |

**Apologies Noted: Ellie Cook, Danny Antrobus, Laura Costa, Nick Pearson,**

**Agenda & Minutes**

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| **Time** | **Item** | **Speaker** |
| 3.00pm | **Welcome and introductions*** Anna Guest welcomed everybody to today's meeting.
 | Anna GuestKaarina Hollo |
| 3.05pm | **Diagnosis and Waiting Lists*** The slide David presented is from the community paediatrics website. They have recently updated their website with information on the slide. This information went live around 4 weeks ago. There has been an increase in Autism and ADHD referrals and requests for assessments. They have raised from 1,500 in 2019/2020 to 4,600 in the last 12 months.
* Teams understand waiting times can be destressing for families. The current data suggests that waiting times can vary from 3-8 years. Teams do want to hear about the community’s concerns and the impact this is having on families. Teams have also been expanded to help tackle this issue.
* Mary highlighted that she is worried about children with a PIP. She asked how they are going to get it with no diagnosis. Not having a diagnosis gives them no chance to access this. How are families going to be able to cope?
* Katie Monette advised that there are some myths surrounding this. You do not need a diagnosis to have access to DLA and PIP, but it can be difficult to access these if people don't know this.
* The team are doing some myth busting work, and this is one of the areas they're focusing on. PIP and DLA should be awarded based on need and not diagnosis.
* Chinyere highlighted that evidence is challenging to access to back up the needs of people who need access to PIP.
* Michelle advised she spends a lot of time doing advocacy work. She has a good success rate but has observed there is desperate need for help and guidance on how to apply for PIP. People struggle with filling in the forms, and there would be higher success rates if people knew how to answer the questions on the forms.
* David acknowledged that PIP needs to be more accessible.
* Anna suggested we have this as an agenda item on a future meeting as it's an important topic that needs to be discussed. All in agreement.
* David shared a flow chart of the stages followed for the SAANS diagnostic process.
* During Covid, the number of Autism referrals increased. The numbers have been declining again recently.
* Wait times are between 60-65 weeks for an Autism Assessment.
* There are currently around 850 people on the waiting list. This is due to having more staff available and more efficient processes being in place.
* Diagnosis' per month have increased since July 2022.
* 88% of people assessed are diagnosed with Autism.
* Rachel Hardy asked what happens to the 12% who don't get diagnosed. Do they get signposted to other services/help?
* David confirmed that the help offered is person centred and will be dependent on individual needs.
* We really need to think of people's needs regardless of diagnosis.
* Chloe asked if there is a way we can provide training for teachers in schools to set expectations early on.
* David confirmed he has seen some work around this.
* Katie Monette advised there are projects in schools to help improve the experience of young people in school settings. In Childrens, it's all about early interventions, and based on need and not diagnosis. We have some good schools in place that will put these processes in place, then unfortunately schools with really poor practice. This project is all about sharing the good practices and spreading them across more schools in Sheffield.
* Chinyere highlighted that SAANS are doing a great job in terms of reducing the waiting lists. There needs to be some clarification on the information that is out there as it can impact the reputation of SAANS if the information doesn't accurately reflect the data.
 | David Newman |
| 3.25pm | **Autism Strategy Next Steps*** Alexis asked how as a board how we want to think about the future of the autism strategy. Do we want to just focus on autism, or do we want to bring in wider neurodiversity such as ADHD? Do we continue being the Autism Partnership Board, or become a neurodiversity board?
* Susan Kirkman advised she would prefer to remain as the Autism Partnership Board. There is still a lot of work to do, and she doesn’t feel it would be proactive to spread things to thinly.
* Katie Drinkwater agreed that there is a need to be talking about other areas of neurodivergence but agrees that this particular board needs to remain as the Autism Partnership Board. We don't have the capacity in this board to address every area of neurodivergence.
* Rachel Hardy advised that she is slightly on the fence as there are many people who are diagnosed with both autism and ADHD, and wonders how these people manage, but at the same time completely agrees with Susan and Katie. There is a lot of misunderstanding around autism still and adding more into the mix might cause more confusion.
* Katie Monette advised she also sees both sides. It was an autism strategy that was introduced nationally so maybe we stick with the national strategy, then if that changes in the future, we revisit this again.
* Sylvia agreed that it's too broad to be called a neurodiverse board. What we should be looking at as a point of review is what the board has achieved in the last 12 years and how it has impacted the lives of autistic people.
* Christine echoed what everyone else said. There's a lot to cover in this area and she doesn’t want this to be further diluted.
* Alexis clarified that as a board the group want to keep the board as an Autism Partnership Board. All agreed.
* Alexis suggested it may be helpful to have some dedicated discussions around themes, particularly around people with learning disabilities and ADHD.
 | Alexis Chappell |
| 3.45pm | Comfort break |  |
| 3.50pm | **Festival Update*** Alexis extended her thanks to everybody who has been involved in the group. There have been lots of good discussions and debate around how the festival should look.
* The feedback we're receiving is the marketing aspect is not landing well.
1. It has been suggested that instead of marketing it as a festival, we will use this as an engagement event over three days instead. The Town Hall has been booked, and we are currently waiting for confirmation from Sheffield University.
2. A key point that has come up from planning is we were potentially putting together an event that excludes people instead of includes. To risk mitigate we're looking at ways people can attend both virtually and in person and having quiet spaces for people to access also.
3. We’re moving this to being more about engagement around the autism strategy, to recognise what we're doing and how we're supporting people.
* Chinyere agrees with this approach. The planning has felt quite disjointed, so it’s better to use this as an engagement event, then look at what worked and what didn't to work towards an Autism Festival for next year.
* Christine agreed that we needed to take stock of the limited time scales and the messages that were being portrayed in the marketing. There has been a lot of interest in stall holders and talk of people wanting to do some artwork. It’s going to be a meaningful few days but may have been a bit ambitious to call it a festival.
* The next planning meeting is this Friday.
* Katie Monette highlighted that it would be useful is somebody could put a document together about what the Autism Festival is so children's can have a better understanding of how they can support.
* Sylvia agreed that this is the right decision. If we're going to make these three days of engagement activities, we need to be clear on what these activities are.
* Chinyere shared that there was a bit of breakdown in communication on who was dealing with the planning of the festival.
* Michelle agrees we have come to the right idea.
* Mary asked if there has been a decision on a name yet. Alexis confirmed this can be agreed in Fridays meeting.
 | Alexis Chappell |
| 4.00pm | **Workstream updates*** Alexis advised that all the workstreams are being put into one action plan.
* Alexis is keen to have a discussion in the next meeting about what these workstreams mean for people.
* An action plan with be circulated with some updates to support that honest discussion around impacts.
* A dedicated discussion around people with learning disabilities, ADHD and community and mental health services will also be set up.
* Alexis updated the group on the Care Excellence Awards.
* <https://sheffnews.com/news/sheffield-cares-excellence-awards-nominations-now-open>
 | Alexis ChappellAll |
| 4.20pm | **Any Other Business*** Nothing raised or discussed.
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Next Meeting: Wednesday 2nd April – 15:15-16:45