

Autism Partnership Board
Wednesday 26th January 2022
Time: 12:30 – 2pm
Via Zoom

Present	<p>Alexis Chappell (AC)– Director of Adult Services – Sheffield City Council (SCC) Simon Richards (SR) – Head of Adult Safeguarding & Practice Development – Sheffield City Council (SCC) Andy Hare (AH) – Strategic Commissioning Manager – Sheffield City Council (SCC) Helena Lath (HL) – Team Manager, Sheffield City Council (SCC) Katie Monette (KM) - Chair of Sheffield Parent/Carer Forum Rachel Dillon (RD) - Strategic Project Manager, Neurodevelopment Programme Melissa Simmonds - (MS) – Adult Autism Project Coordinator VAS/Autistic Adult/Parent Carer Liz Friend (LF) – Parent Carer, Trustee Sheffield Autistic Society Robert Carter (RC) - Senior Commissioning Manager - Clinical Commissioning Group Emily Morton (EM) – Chief Executive, Disability Sheffield Katie Foster (KF) – Social Work Consultant – Sheffield City Council (SCC) Megan Freeth (MFr) – Lecturer in Psychology - University of Sheffield Carolyn Bealby (CB) – Employment and Training Group, Sheffield Asperger’s Parent Action Group (SAPAG) Susan Kirkman (SK) - Family Carer / National Autistic Society Katherine Robertshaw (KR) - Deputy Director, Sheffield Accountable Care Partner, CCG Abbie Sissons (AS) – Children’s and Young Peoples Keyworker for Autism and/or LD, CCG Caroline Stiff (CS) – Adult Care, Commissioning (SCC) Lacey Hague (LH) – Amy Weston (AW) - Commissioning Manager, Learning Disabilities and Autism CYP and adults- Sheffield CCG Greg Pursehouse (GP) - Children and Young People Keyworker - Autism and Learning Disabilities Jane Goodwin (JG) – Researcher, Newcastle University Emma Nielson (EN) - Researcher from University of Nottingham Mary Vere (MV) - Parent Carer, LD Board Member, Healthwatch, Sheffield Carers Voice, Flash John Kay (JK) - Parent carer / Autistic Adult Ann Mitchell (AM) – Senior Business Support Officer – Sheffield City Council (SCC)</p>		
Apologies	Graham Nield, Nicola Shearstone, Georgina Parkin, Charlotte Worthington, Helena Johansson		
Chair	Alexis Chappell	Minutes	Ann Mitchell
Item 1	Welcome and apologies		Action
	Alexis Chappell, Chair, welcomed all to the meeting and introductions were made.		
Item 2	Research on Suicide & Self-Harm Safety Plans - Jane Goodwin and Emma Nielson		Action
	<p>Jane Goodman explained she and Emma Nielson have been working on a Research Study into Suicide and Self-Harm Safety Plans. They had brought along a series of slides to explain the study, which had been shared with members before the meeting. Jane explained that suicide is unfortunately much more common in autistic persons than it is in non-autistic persons. They have been working with autistic adults and their carers whilst undertaking the study. Emma then went through the slides and explained each one.</p> <p>Towards the end of the slides Jane explained the ‘Aims and Research Questions’ slide, stating they will be working on a future trial of the Safety Plan and will be working</p>		

with non-NHS partners, explaining this research study is being funded through the Public Health Programme.

Jane confirmed they have now completed Stage 1 and Stage 2, in which they undertook a feasibility study which involved 10 autistic adults with experience of self-harm and suicidal thoughts. They will now be moving onto Stage 3 where they are looking for 10 further autistic adults with experience of self-harm and suicidal behaviours.

Stage 3 was then explained, where autistic persons can self-refer themselves to the study if they wish to but only if they are currently not in touch with any other non-NHS organisations. Stage 3 will aim to put together an autism adapted safety plan which will be monitored regularly to see how it is going.

Jane explained that part of the study involves offering training, in the form of 30-minutes of pre-recorded slides and then zoom meetings with the research team. After this there will be a 3-hour workshop to go through how to put together the safety plan.

She stated there are two routes to become involved in the study, either self-referral or referral through a partner organisation.

Jane and Emma's contact details were then given for anyone who would be interested in becoming involved in the study, and members were asked if they had any questions:

AASP@newcastle.ac.uk

Firstly, Alexis thanked Jane and Emma for their presentation and asked members if they had any comments/questions.

Carolyn Bealby thanked Jane and Emma for their interesting presentation and stated she hoped this will influence the NHS. She asked who they would be feeding information to within the NHS from the findings of this study. Jane responded by stating the study is funded by a research arm of the NHS. She stated there will be a feedback event which will include autistic adults and organisations.

Liz Friend asked how the information gathered in this study will be used in the future. She stated she has one observation in that autistic people require lifelong support. If this study could lead to more support for autistic persons that would be good. Emma responded to say they are hoping to do a second study.

Caroline Stiff then stated, with regard to long-term planning, if this study can influence this that would be beneficial. She noted that a safety plan might not work for everyone, but she understands the reasons for the study.

Emma then stated there will be a 6-month follow-up where they will be asking participants what they think of the safety plan. She stated so far they have had one person who had problems with their safety plan but they discussed this with the person.

John Kay asked what the timeframe is for the results of the study. Emma responded by stating they are still recruiting autistic persons until May of this year then there

	<p>will be the 6-month catch-up and a couple of extra months to gather information so it will probably be around Spring of next year before they know how the study has gone. Alexis then suggested Jane and Emma could return to a future APB meeting to give members an update. They both agreed this would be good.</p> <p>Action: Jane and Emma to be booked into a future APB meeting to give an update on their study.</p>	<p>KF</p>
<p>Item 3</p>	<p>Improving post-diagnostic support for Autistic Adults – Megan Freeth</p>	<p>Action</p>
	<p>Megan Freeth introduced herself, stating she works for the University of Sheffield. She explained she had attended the meeting today to give details of another research project which is being funded by NHS England and Autistica, focussing on improving post-diagnosis support for autistic adults.</p> <p>Megan had come to talk to the board today as she wanted to ask members thoughts on whether they felt this project was needed and is the project plan appropriate.</p> <p>Megan had brought a presentation of slides which she read through. This presentation had also been shared with members prior to the meeting. She confirmed there will be workshops taking place, the first one being on 21st February; to understand current practice and to give a list of delivery organisations. Workshops 2-4 will be the ones where they invite autistic persons to attend. She explained the content of the workshops:</p> <ul style="list-style-type: none"> • Strengths and needs • How to implement support via low-intensity tech-based tools • Potential barriers to engaging with a tech-based tool <p>Megan confirmed attendees to these workshops will be paid for their time.</p> <p>She then went on to explain that Workshop 5 will entail consideration of the NIHR project proposal. Attendees from all workshops will be invited to review the key elements.</p> <p>Project Outcomes:</p> <ul style="list-style-type: none"> • A project outcomes report will be produced. • NIHR RfPB funding proposal • A Policy briefing. <p>Megan then repeated the questions she wanted to put to APB members:</p> <ul style="list-style-type: none"> • Is the project needed? • Is the project plan appropriate? • What should low-intensity support look like? <p>Alexis then thanked Megan for her presentation and asked members if they had any questions.</p> <p>Susan Kirkman stated there has already been a lot of work on this subject undertaken in Sunderland/West Midlands/Leicestershire areas. She suggested Megan contact them as they may have some useful information. She stated she would share an email address of someone who has been involved in this work. Megan thanked Susan for this and agreed that she would contact the person.</p>	

Sharon Brookes commented she feels this is a good project and feels low-intensity support is very important. She stated SAANS would want to become involved in this study.

Carolyn Bealby stated the project does sound interesting and it is inexpensive for people to access. Megan agreed that this would be low-cost to organisations. Carolyn stated she would like to contribute to the workshops. Megan thanked her for this and urged all members to contact her if they were also interested in becoming involved.

Robert Carter thanked Megan for her presentation and confirmed the CCG commission a post-diagnosis service from SAANS. He asked who was involved in this from NHS England. It was confirmed this was Lorcan Kenny. Robert then suggested Richard Hill, from the ICS as someone who it might be beneficial for Megan to speak to.

Rachel Dillon then suggested access to support could be given pre-diagnosis. She stated this would be a better option when persons were on a waiting list. Megan thanked Rachel for this suggestion.

Liz Friend commented it seems the focus of this study is on a tech tool. She mentioned Brain & Hand, which is an expensive subscription service. She stated this is supportive as there is a person available to speak to if required. She stated this could be helpful with this new tech tool. She then agreed with the point Rachel made about pre-diagnosis support being important too. She supports people who are on the waiting list so knows extra support would be welcomes. Megan thanked Liz for her interesting points.

Megan then stated she agrees with Rachel's suggestion re giving support to persons whilst they are on the waiting list, therefore pre-diagnosis and stated there are some other organisations who offer this support.

John Kay asked if the tool was able to indicate an increase in need – so this information could be passed on to appropriate services. He stated it would need some sort of feedback to trigger further support. Megan responded by stating this was a brilliant suggestion, which is something they would consider including in the tool.

Megan then thanked members for their interesting points. She stated she wanted this service/tool to emerge from what people want it to be. She stated realistically this will be a low-intensity tool. She stated that in around 4-5 months she should have more information on this study.

Alexis then thanked Megan for her presentation. She suggested the following:

- Megan to share her details to members so they can contact her if needed.
- For Megan to come back to a future APB meeting, possibly around July, to give members an update.

Action: Megan Freeth to attend the July APB meeting to give an update on the study.

KF

Item 4	Autism Strategy Action Plan – Simon Richards	Action
	<p>Simon Richards stated the working group have been working on putting together an Autism Strategy Action Plan, which is now taking shape. He stated Katie Foster has been working on putting together the plan, which has now been shared with APB members.</p> <p>Simon stated the plan is a statement of intent. There will be overarching actions, which will make a difference to autistic persons, but he needs members to confirm if this is what they want. Simon also commented that the working group agreed they should only prioritise a few actions at a time as trying to do everything at the same time does not work.</p> <p>Simon confirmed the first action they are looking at is mapping. This is to look at what is already happening, and which organisations are involved. He stated Melissa has done a great networking job recently, so some of that work is already there and taking place.</p> <p>He stated we need to hold people to account, and the APB should have a role in this.</p> <p>Another action is Communication, Simon stated we need to develop a communication plan, which has equalities, inclusion and diversity included in it.</p> <p>The work should be co-produced with autistic adults who can give their own experiences and what actions have made the most impact in their lives. They need to look at what priorities people feel are important.</p> <p>Simon stated he wanted members to state how they want things to move forward.</p> <p>Alexis then thanked Simon for the update and thanked the working group for their clear focus. She asked members if they had any comments/questions for Simon.</p> <p>John Kay stated could the board agree that the minutes from the APB meetings can be put on the APB SCC website. He stated SCC should be responsible for this.</p> <p>Emily Morton then stated with regard to the implementation groups can it be agreed that a lead person is put in place, who is from a statutory organisation, as we need someone who has the authority to do things. Also, with regard to membership she feels there are other people who could be involved, as we don't want to over-capacitate ourselves.</p> <p>Rachel Dillon then stated, from a Children and Young People point of view it is great that this is being done. She stated she is coming to the APB meeting next month to do a talk about what they are doing in the Children and Young person's field so it would be good to align the two. She queried what problems we are trying to fix in Sheffield. She stated to get a list of actions we need to understand what our problems are to be able to address these.</p> <p>Kathryn Robertshaw stated we need to measure progress and impact so this should be added to the Action Plan. She stated improving awareness in health care staff would be good to see also.</p>	

	<p>Alexis then responded to John’s point re the minutes being published on the SCC website, by stating she would agree with this and will speak to the relevant persons.</p> <p>With regard to Emily’s suggested of there being a statutory lead on each workstream, she stated ownership of this is to be looked at by the working group.</p> <p>With regard to Rachel’s suggestion that Children & Young People align with adults she suggested Rachel meet with Simon and Katie. Rachel then suggested sharing this with their Task and Finish Group</p> <p>Action: Simon and Rachel to discuss ways to align Children & Young People and Adults.</p> <p>Alexis then stated with regard to outcome measures making a difference, she suggested Kathryn and Jenny Milner should look into this.</p> <p>Action: Alexis suggested Kathryn and Jenny Milner could meet with Simon and Katie to look into how to measure progress against outcomes from the Action Plan.</p> <p>Alexis then stated with regard to Simon’s points, as follows:</p> <ul style="list-style-type: none"> • Do members think the approach is ok and on the right track? - All members agreed. • Are members happy with the Mapping exercise? – All members agreed. • Priorities – are these appropriate? What are the first ones we should look at? Susan stated she feels Housing is very important, as is awareness-raising. John again mentioned that he feels the APB minutes should be put on the SCC website, by the next meeting. He stated if someone typed in ‘Autism’ to the SCC website then they should be able to access the APB minutes. Simon responded by stating there have been issues in SCC with getting things done re the website, which is not good enough. He stated he has asked Alexis to become involved in this to enable this to be prioritised. It was agreed that Simon and Alexis would meet to discuss this further. Carolyn then stated that to her, the most important things to work on are appropriate housing, support for those who do wish to work, and post-diagnostic support. <p>Action: Alexis and Simon to meet to discuss prioritising website work.</p> <ul style="list-style-type: none"> • Rachel then stated that their priorities, within Children & Young People are support for all, plus pre- and post-diagnosis and early identification. She stated early identification could stop children and young people suffering the way they are now. <p>Action: Alexis suggested Rachel and Simon meet to discuss aligning the Adults Strategy Action plan with the work being done within Children’s and Young People’s support.</p> <p>Alexis then thanked everyone for their frank discussions. She sated we need to work on trust building. She suggested that Simon and Katie could finalise this feedback.</p>	<p>SR/RD</p> <p>SR/KF/ KR/JM</p> <p>SR/AC</p> <p>SR/RD</p>
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	<p>Action: Simon and Katie to incorporate member’s feedback into the action plan document.</p> <p>Alexis then stated, with regard to the Minutes/Actions and Action Plan, the working group should continue to meet to finalise the plan.</p>	SR/KF
Item 8	AOB and Agenda Setting	
	<p>LeDer – Susan Kirkman Susan wanted members to be aware that the LeDer programme will now include every autistic person, not just those with LD. She stated we need to agree how we are going to identify all autistic persons, who do not have LD. She stated GP surgeries may have some information and PiP may also have some data but we need to find ways of publicising this is in place. She asked members for any ideas on how we can contact people.</p> <p>Carolyn s asked what LeDer is. Susan explained LeDer is the organisation who review deaths in persons who have died earlier than they should have. Carolyn stated she was involved with some work with Liz Tooke on gathering data on autism, but she doesn’t think anything was done with this work. She noted that some people aren’t assessed, so how would we know about them. She stated the only other way would be through GPs, which she things Liz Tooke is currently working on. Susan agreed that there are some people with Autism who don’t want to be counted.</p> <p>John suggested contacting Universities as they would possibly have information on whether the student has autism, but the persons may not want to divulge this. Susan stated they are only counted if they have died. Mary suggested perhaps a tick-box could be added to the death register form, for example ‘suspicion of Autism’. She also stated, in a patient’s medical records could whether they have autism be highlighted at the top of the page?</p> <p>Alexis agreed this is very complex and suggested this should be raised at the S/G Board. Alexis agreed to contact colleagues in CCG and could then come back to the APB for a broader discussion. Susan suggested, if contacting someone in CCG about this, it should be Anita Winter. Alexis thanked Susan for this and stated they could bring back some proposals.</p> <p>Action: Alexis to speak to colleagues in CCG regarding counting Autistic persons. A discussion will then be brought back to a future APB meeting.</p> <p>Caroline Stiff kindly shared the link for LeDer: https://www.england.nhs.uk/learning-disabilities/improving-health/mortality-review/</p> <p>Minutes & Action Logs on Agenda – this should be in place for the next meeting.</p> <p>Katie confirmed she has been working through the action plan and ensured it would be put on the agenda for the next meeting. Robert stated the Action Log could be circulated to members to agree which sections we need to park and which ones to go forward with.</p>	AC

	Alexis then thanked everyone for attending and the meeting ended.	
	<p style="text-align: center;">MEETING CLOSED The next Autism Partnership Board meeting will be: Wednesday 23rd February 2022 Time: 12:30pm – 2pm via Zoom</p>	