**Thurrock Adults Autism Action Group
Wednesday 4th May 2016**

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| **Topic** | **Discussion** | **Agreed Action Points** |
| 1. **Welcome, introductions,**

**apologies**  | **Attendees:** Ashley Woodward, CaPa/Parent/Carer – Co Chair Kelly Redston, Integrated Commissioner – Co Chair Andrea Walter – SAFEBeth Crossley – Service UserInspector Kevin Whipps – Essex PoliceJane Flatt – TreetopsAndrea Valentine – Healthwatch ThurrockMo James – PATTIan Evans – Thurrock CoalitionRachel Ely – Minutes **Apologies** Neil Woodbridge, Kim James, Bill Clayton**Welcome** By Ashley Woodward Ashley Woodward welcomed everyone to the meeting. Introductions were made.  |  |
| 1. **Minutes of the last meeting & Action points from February meeting**
 | Ashley asked everyone to check the minutes. Ian Evans asked that everyone check them for accuracy page by page. The minutes from the last meeting were signed off and seconded by Andrea Walter.Ashley asked whether Andrea W. had emailed Kelly with regard to the terminology in minutes, to apply to people with Autism and Asperger’s. This has not yet been actioned.The group were unable to update on the status of Neil Woodbridge’s action points re: the Capital Grant (speaking to Michelle Lucas) and the music group (arranging a visit to the studio for the board)Bill Clayton has provided an update on the Autism Champions project (copy attached to these minutes)This and the other action points in these minutes are covered in the agenda points for this meeting. | Follow up with Neil on the status of his actions |
| 1. **Update on Autism Champions Project**
 | Kelly Redston talked through the update that was provided by Bill Clayton on the project. The implementation, moving forward in the community. She highlighted that they had looked at the ‘Dementia Friends’ framework as previously mentioned but feel that it should be more specific and not in the same format – more Thurrock and Autism specific.Kelly gave everyone a few minutes to peruse the document and asked for any comments/feedback. She clarified that at the moment timescales have not been set, as the draft needs to be approved before that is done.Ashley Woodward asked how or what materials would be used, would these be worked on nationally and then the material shared? It was agreed that it needs to be framed to the wider community and a person’s everyday roles/experiences should be shared to increase understanding. Ian Evans asked whether this material existed electronically. Kelly confirmed that regionally yes there were examples and discussed what was already there, including an interesting presentation around gender roles.Andrea W. asked whether the project is out to tender to local charities? Which Kelly confirmed was the idea but highlighted that it would more than likely be TCIL etc. that manages the project as this would be most appropriate. Kelly confirmed that the LA would be happy for people to apply for more funding to extend the project if necessary. This is the next step and also why there are not yet any timescales.Kelly asked that everyone in the group be interactive with their input, as the input should not just be created by the LA officers. Andrea W. asked whether there would be a training element included in the project? Kelly confirmed that the set up and structure would be put into place by the LA and will be included in the tender/grant. She confirmed that there was a new round of funding due soon. | Kelly can provide national examples so that the group can see what is already out there that is useful. |
| 1. **Update on the Assistive Technology Initiative**
 | Ian Evans and Ashley Woodward are heading up this initiative.They highlighted that they were meant to meet with Barrie Ellis (Assistive Technology Specialist) to analyse what technology people wanted from the £18k budget available.Ian spoke about the project and that the facilities and access points for hire/loan would be at TCIL and Beacon Hill. Ian went through a list of the things that have been suggested as loan/hire items (one of which was the book, ‘Girl with the Curly Hair’). Ian spoke about items on the list, some of which Ashley Woodward and Ian had been able to see, as Barrie brought some items to a meeting to show them. Including:* Sensory equipment
* Apps
* Ipads and Ipod touches
* Weighted items
* Communication items
* Squeezewear

TCIL have agreed to be the storage point for the hire/loan equipment, with the possibility of an afternoon where people can access the initiative.Ian spoke about there being a single point of access and the possibility of an Autism Champion fulfilling that role? It was also suggested by Kelly Redston that there could be a button on the information and advice portal. There was a discussion around whether the autism hub could do this?Andrea W. brought up the issue of whether there is any provision for breakage of items or training for those persons in using the equipment appropriately. Ian agreed to look into this.A discussion was held around using some of the items in cells such as wireless headphones etc. for persons in distress after this was raised by Kevin Whipps. It was agreed that this would be a valid idea in order to help alleviate stressful situations in custody cells.It was agreed by all that the way forward was to have a wide range of items and that it would be impossible to please everybody.Andrea W. suggested that once the initiative is up and running it may be useful to have a feedback form on how useful the item was/is. This would then provide feedback to the LA if you want to prove that the service is useful. In Southend they have to give statistics etc. | Ian Evans will send a list around to the Autism Action Group of possible loan/hire itemsIan to send a link to the group with details of the Autism Hub.Kelly to look into getting the Autism Hub at a future AAG meeting to talk to the group/do a site visit.Ian Evans and Ashley Woodward to speak with/meet with Beacon Hill regarding the spending of the grant |
| 1. **Transforming Care agenda Young Person’s Mental Health – NELFT information**
 | Kelly Redston talked about the Adult Autism Assessment. She mentioned that she has a meeting with the provider ‘SEPT’ next week. She spoke about there not being a clear pathway because it is such a niche service. It is not Thurrock specific, it’s an Essex/Basildon service. There is uncertainty with what is happening with the CCG.Kevin Whipps asked whether it is a stay as it is or a mapped to model service. Kelly spoke about the complexity of the service and that it is not commissioned on a Thurrock only basis/not stand alone (LD, mental health work).There was a discussion about the frustration with the diagnostic pathway for adults, the pathway for children is a lot clearer (where the pathway is generally through an educational route with the parent having the option to go through health). Andrea W. mentioned that the waiting list can be up to two and half years in adult services.Mo James mentioned the difficulties with the autism diagnosis for the 11+ age group (generally girls), as the paediatricians will not see those that fall into that age bracket.Andrea W. confirmed that there were similar issues in Southend with an eighteen week wait in Chelmsford and Colchester.Kelly Redston passed around a handout detailing the new service from NELFT – the EWMHS (Emotional wellbeing and mental health service) (attached)There was a discussion about the document and the service being a single point of access. It was agreed that it would have been helpful to have NELFT give a presentation about the new service at the group.Andrea W. mentioned the fact that CAHMS was always quite difficult to navigate/ access. Parents can self refer to NELFT, which empowers individuals.Kelly has feedback for the 5-13 age group which she is happy to share but not as part of the group.Kevin Whipps spoke about the fact that at present with regard to hospital admissions they have to take persons to Colchester. Kelly said that the new service does give a wider scope but the beds are full. The group talked about the availability of beds for mental health patients, with Kelly saying that there is the possibility to commission on an ad hoc basis.Ashley spoke about Carers and siblings needing support too, as mental health has an impact on the whole family. Kelly introduced the Transforming Care Agenda Document, which covers and raises quality, best practise and the most cost effective way forward (local need may not make money sense).Everyone looked over the document and highlighted that the first paragraph spoke about a focus on learning disability and mental health. It was agreed that autism needed a separate discussion because it is difficult to pick apart because of the differences between ASD and learning difficulties. Kelly said that the first meeting to discuss the Thurrock perspective is tomorrow, with a pre-meeting with Zandra. Kelly said there would be a discussion tomorrow about whether autism is included in the wider picture. As well as transitioning issues, service offers (adults and children and the differences), taking it Essex wide (with ASD being considered separately Essex wide). There was a discussion held around whether things would be discussed from a Thurrock wide perspective and parallel pathways as needs aren’t always met from teenage-hood into adulthood with legislations and guidelines suggesting that it should be 3 months when in reality it is 2 and half years. It was also raised by Ashley that she felt that the parents groups should be separate from the pan Essex transforming care board. There was a discussion held around the difficulties where undiagnosed. Kevin asked whether there were any actual figures of those whom it is applicable to (only those accessing services already), pre-diagnosis not known.Everyone agreed that the TCA would help to implement legislation. Kelly Redston thanked everyone for their feedback. |   |
| 1. **A.O.B. (Including next meeting date)**
 | A discussion was held about the new music group/recording studio. Mo James mentioned that her son is accessing the service along with about half a dozen others (with high needs) with TLS funding a music teacher and some of the grant monies being used too.It was suggested by Andrea W, that maybe it needs to be written up as a project and also whether there was a waiting list and were schools aware, in case of accountability. Kelly however clarified that for the moment the scheme is a pilot, with the potential for becoming wider (with additional funding).Kevin Whipps gave the group an update on training within the police around mental health and learning disability, which included autism awareness training – this took place on 1st April. Link in Bill Clayton to autism awareness, align Thurrock in with Essex and their initiatives, as the 999 cards are not autism specific. Kevin circulated a handout of possible alert cards to Ashley.It was highlighted by Kevin that he felt that there was more training needed on understanding.There was a discussion held around where there is no diagnosis what the procedure is and the difficulties where people don’t at first appear ‘autistic’. Mo highlighted that it was important to step back and try and spot the signs. Andrea spoke about looking for nuances in personality and awareness of the autistic spectrum (although Kevin said that normally in the 11-17 age bracket the parents often tell the custody officer).Kevin said that the difficult often wasn’t with them but because they could only take them to a certain point and after there was a distinct lack of awareness in the crown prosecution service, amongst defence lawyers, barristers, magistrates etc. Beth Crossley asked whether the advocate for the person would assist with this, is there someone provided? Kevin said there is not always someone in court. It does help when the judge is made aware. It should be like translation services, an autism strategy, single point of access across the board.Meeting dates:3rd August 2016; 2nd November 2016 10am to 12 noon – CR 1 – Civic Offices, GraysIn addition Ashley Woodward, Ian Evans and Kelly Redston to meet monthly going forward. | Neil Woodbridge to provide feedback at the next meeting.Kevin to get a copy of the autism awareness cards (East Anglia) by the next meeting. |