

‘The Art of the Possible’ Listening Event

**Redesigning services for people with
Autistic Spectrum Condition (ASC) and
Attention Deficit Hyperactivity Disorder
(ADHD)**

Summary and Next Steps

The Art of the Possible Listening Event brought together service users and families and a range of stakeholders to comment on the progress made so far by NHS Eastern Cheshire Clinical Commissioning Group (CCG), in relation to the redesign of Autistic Spectrum Condition (ASC) and Attention Deficit Hyperactivity Disorder (ADHD) services in Eastern Cheshire. Feedback was collated into positive comments about the proposed pathway, questions and considerations and negative comments.

“Family support is imperative throughout”.

“At the moment there is no information, no networking and no signposting. New pathway is much better”.

“Many parents see parenting courses as generic and insulting. The name implies that people are bad parents and people can't get anything done until they have been on one.”

“Who will be triaging, one person or a panel? And will they be highly qualified?”

Generally people felt that the pathway model was very positive. There was support for the triage element, though some worries that this would exclude some families before they were able to access a full assessment. The five pathways were felt to be person-centred and suitable to meet all needs. There was support for the idea that all agencies and organisations need to be working collaboratively to support people with autism and ADHD and a consensus that information sharing needed to be improved to facilitate this. Transition from early years to school age and school age to adult services was raised as a concern and it was noted that the pathway needed to be seamless for service users. It was felt that exit strategies needed to be existing but people needed a way of re-entering services if and when needed.

“Need better links between early years and CAMHS.”

“Everybody should act as a support stepping stone and give parents the confidence to try other services”

“I want to tell my story only once”.

“Everyone needs a better knowledge of all the services that are out there including 3rd sector/private.”

“Referral form needs to list all possibilities and link in to assessments that already exist – EHCP, CAF, CN/CP and can be used post diagnosis.”

“Post 12 diagnosis is important, especially for girls.”

Possible Solutions:

- Toolkit for referring professionals, as part of the watchful wait period.
- Use of CAF and other assessments pre and post diagnosis.
- Triage section to be remodelled as a family support level – offering not only triage but also signposting to support, including parent peer support, other agencies, online and digital resources, parenting courses (maybe renamed?)
- Triage element to be further defined.
- Education and consultancy for all professionals – possibility of online training and parent/carer input.
- Link with Paediatricians and Child Development Centre.
- Include outcome measurements.
- Show exit points and also re-entry points and include fast track options.
- Inclusion of parent/carer self-referral option (to family support level).
- Inclusion of Cheshire East Autism Team for assessment and diagnosis.
- Information and support to be offered as a key intervention for all pathways.

Next Steps:

The CCG Governing Body will make a recommendation on the 30 September which will inform us of the next steps.

Based on this decision, over the coming months, there will be a series of focus groups for service users, parents and professionals where we can discuss how to implement changes to the model and start to work together to improve services. A project group will be formed to make progress towards an integrated model of care for young people and their families and carers.

The first of these focus groups will be for parents and carers and will be held as part of Space4 Autism's AGM on Monday 19 October – click on the icon below for details.



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