

An emerging initiative for teenagers, their parents and siblings

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With increasing numbers of older children and teenagers being identified as on the [Autistic Spectrum](#) (Centre for Disease Control and Prevention, 2014; Matson & Kozlowski, 2011) we have seen a clear shift in the demographic of referrals to our service. Although the assessment process for older and more complex children has been a service challenge, it is the gap in the offer of post-diagnostic support that has been harder to address. Traditionally we have endeavoured to support children with Autism Spectrum Disorders (ASD) by providing their parents with a robust psycho-educational framework, one that encourages them to understand their child's development in relation to the challenges ASD poses (e.g. the National Autistic Society EarlyBird Programme & ASCEND Parenting Programme). This approach has been very successful when working with parents of pre-school and primary age children. However, when involved with teenagers, we have begun to realise that this framework might not be as appropriate.

Research indicates that early-intervention support for families in the process of coming to terms with a diagnosis is likely to build resilience and help prevent mental health difficulties commonly found co-occurring (Simonoff et al, 2013). We were aware that Pegasus, comprising a psychoeducational group for teenagers meeting concurrently with a psychoeducational group for parents, had some research support for benefit. (Gordon et al, 2015).

Through discussion with parents it became clear that they wanted a support package that would allow them and their teenage child to develop a shared understanding of ASD, for this to be accessible to siblings and for the focus not to be entirely around autism.

In light of this, the workshop we developed had three core aims:

1. To enable parents to recognise 'teenage behaviours', know the challenges that ASD will pose and help their teenagers to develop strategies to overcome these
2. Offer the teenagers an experience that ensured participation, enjoyment and consideration of their strengths and difficulties in relation to their ASD diagnosis
3. Enable siblings to be involved in this process alongside teenagers with ASD.

As with other aspects of our work we liaised with education and managed to secure a venue and enlist the help of the educational outreach teacher. This link proved very important as she knew the teenagers attending. We also managed to secure funding to employ a music company to run two music sessions for the teenagers, which again was a fantastic success.

Outline of the intervention

From the outset we knew that to achieve our core aims the sessions needed to be paced and managed carefully so all participants could be provided with information about ASD in a meaningful way. We felt it would be important to offer the teenagers a mix of talking and non-talking activities, as well as providing the whole group with opportunities to be together.

The two-day workshop took place over the school holidays and was structured as follows:

	Parents	Adolescents	Siblings
Day One AM	Just Bead It (Portnoy, Girling, & Fredman, 2015)		Music workshop
Day One PM	Psychoeducation	Psychoeducation: strengths and difficulties exercise	
Day Two AM	How to use visual strategies		Music workshop
Day Two PM	Music performance and autism quiz set by the teenagers for parents		

The Beads of Life approach (Portnoy et al. 2015) was used with parents to facilitate them telling the story of their child receiving an ASD diagnosis. Psychoeducational sessions for parents involved discussions about the key theories of ASD and how these were likely to impact their teenagers, including Theory of Mind, Sense of Coherence and Executive Functioning (resources used from Williams & Wright, 2004). The psychoeducational session for teenagers involved exercises identifying famous people who have overcome their own learning difficulties or special needs to go on to have a successful career (Pegasus). It also involved the young people identifying their own strengths and difficulties using the Triad of Impairment model. The session on visual strategies was facilitated by a local specialist autism teacher who brought many examples of visual tools that can be used for teenagers with ASD. The music workshops were facilitated by two musicians experienced in working with young people with disabilities who emphasised spontaneity and collaboration.

Reflections on the workshop

Parent participation

Parental themes about their child's vulnerability, lack of social interest, restricted interests, naivety and poor emotional regulation were noted throughout the workshop. For parents of girls, concerns about friendship choices, resolving conflict and fear of sexual exploitation were raised as major concerns. What emerged during the parent-only session was a natural tendency for the group to share and problem solve as these issues emerged. The respect and appreciation of their children's differences and family differences was tangible. This very quickly enabled the parents to bond. The conversation over the two days moved naturally between being therapist led to parent led. The end point was a genuine expression that the experience was really useful and, as expected, linking with other parents facing similar issues was highlighted as the most beneficial aspect of the event.

For us, seeing parents enjoying their children's participation in the music sessions and laughing together about the obvious 'teen' stuff they were experiencing was infectious and inspiring.

Teenage feedback / facilitators reflections

We had predicted that it might be difficult for the teenagers to express their thoughts about the day and so observations and reflections on their participation, mood and level of engagement were noted.

The most significant was the change in teenagers' mood, motivation and level of engagement from day one to day two. On day one they each arrived anxious, uncommunicative and reluctant to participate. Several were also observably cross with their parents, which prompted parental discussion about how they had 'managed' to get their teen to the group. Day two, however, started on a high with all teenagers seeming more confident and ready to get started. The music session was able to bring the teenagers and their siblings together in a cohesive and unifying way culminating in a performance for the adults, which everyone was clearly proud of. In the afternoon the teenagers then went on to write an ASD quiz for their parents, which we used in the final session. Again this shared experience was incredibly powerful and engaging.

Conclusion

The piece of work was a collaboration of health, education and a private music company. It relied on all to be enthusiastic, flexible and optimistic as this was the first time we had offered such an intervention. Although the event was small scale, it was a palpable illustration of how getting the context and content right is enabling for [ASD](#) teenagers. The parents and teenagers arrived anxious, annoyed and uncommunicative on day one and left as smiling families, having enjoyed a successful shared experience. All of the families said that they would be interested in attending follow-up workshops and voiced that it would be good to have siblings attend as well. This pushed us to seek more funding and we have now secured charitable funding to run further projects during 2016.

Conflicts of interest

The author has declared that they have no competing or potential conflicts of interest in relation to this article. The views expressed here are those of the author and do not necessarily reflect those of the Association for Child and Adolescent Mental Health.

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