

Parents advising researchers: Experiences from the 'Beating Anxiety Together' study

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There is increasing recognition that users of services have a great deal to offer to research that is far more than simply taking part in a study. This article describes our experience as parents advising a research study of group therapy for young people with autism spectrum disorder (ASD).

The study

Beating Anxiety Together (BAT) was funded as a pilot randomised controlled trial by the National Institute for Health Research. It aimed to find out if group cognitive behaviour therapy adapted to suit young people with ASD would be acceptable to them and their parents, and have the potential to reduce their anxiety.

Parents advising researchers

Parents and other service users were involved at all stages of the study, from making sure the right questions were being asked, through to design and management, and publicising the findings.

First, a survey of anxiety in ASD was carried out through Daslⁿe, the database of children with ASD living in the North East. Next, parents (again recruited through Daslⁿe) were invited to a lunchtime group to discuss their children's anxiety. Examples of what caused anxiety and how children responded were provided by the parents, and some anonymised examples were included in a parent questionnaire.

Discussions with the service user representative in the local mental health trust also informed the study design. The service user representative advised that all families should be offered a chance to attend therapy groups, and that ideally the groups should be held in community settings rather than a clinic.

Once the study was up and running, Deborah (parent of a young person with ASD and Manager of the National Autistic Society (NAS) Resource Centre) and Dave (also a parent of a young person with ASD) joined the BAT Steering Committee. The Steering Committee was responsible for overseeing the running of the study and providing advice to the researchers on a variety of aspects, such as the content of the information sheets given to young people and parents, the wording of new questionnaires, how to ensure that the families who were randomised to 'delayed therapy' understood what the arrangements would be at the end of the study, what to include in the report of the assessments given to individual families, and editing the summary of findings for parents and professionals.

"Shortly after I took up the post of Resource Manager [of the National Autistic Society], I was invited to become an advisor for the BAT study. I was extremely keen to become involved although I knew that I had little experience in this type of work. At the same time I was asked to help identify another parent representative to join the Steering Committee. I spoke with Dave, a parent who had previously contacted me through the NAS, to ask if there were any services in place to help reduce his son's stress levels at school. Even though his son was too old to be included in the pilot evaluation, I mentioned the BAT study to him and he contacted Helen, the psychologist leading the study. Dave felt that if his son couldn't be involved directly then he would have first hand experience to give, and he would find out more that could help him and his son."

Deborah

“Equipped with a personal copy of ‘Exploring Feelings’ [the therapy approach materials used in the study] I sat in Steering Groups, a lost lone voice amongst a sea of academics and at first struggling to come to terms with what they were hoping to achieve and the language they were speaking. But gradually I came to terms with the project and started to take an active role and was never afraid to stop the debate if I didn’t understand the terminology. Initially we discussed the name of the project and a logo. That took two sessions of quite lively debate! We continued to provide a parental perspective and ask questions that we thought the parents of children on the autism spectrum might want answers to, before they volunteered their children onto the pilot study.”

Dave

We were able to ensure that the BAT team used clear language and that the only acronym in any of the documentation was BAT. As parent representatives we also made sure that plans were developed from the start about how best to publicise the study, so that families could hear about the research and its findings. For example, we suggested that recordings could be made of some parents and young people being interviewed about their experiences. This resulted in an edited DVD that can now be used to disseminate the findings of this pilot study and to explain to potential participants in a bigger multi-site study what is involved in the groups. We found having us both on the Steering Committee worked well. We felt supported by the other members of the Steering Group and we were also able to give different perspectives from our own experiences.

Final thoughts

The work involved to get this project up and running has been a real eye opener to us and we feel that the work was rewarding and worthwhile.

“My advice to all parents would be to grab an opportunity like this if you get the chance. It has been challenging, rewarding, educational and I’ve met some great people en route.”

Dave

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To read more about the BAT study and its findings see

McConachie, H, McLaughlin, E, Grahame, V, Taylor, H, Honey, E, Tavernor, L, Rodgers, J, Freston, M, Hemm, C, Steen, N, and Le Couteur, A. (2013) Group therapy for anxiety in children with autism spectrum disorder. Autism doi 10.1177/1362361313488839

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