



The Autism Family Experience Questionnaire (AFEQ)

Developing a Questionnaire to Measure Family Quality of Life and Parent Priorities for Early ASD Intervention

Background

- Research into interventions for children with ASD often focusses on whether the intervention brings improvements to children's communication and language skills, play, IQ, or behaviour. These are important child-centred goals. However, these are the intervention priorities set by researchers and clinicians. **What changes do parents want from early ASD interventions?** And is it possible to measure changes in these key areas within an intervention trial for autistic children and their parents?
- We wanted work in partnership with parents to design a questionnaire that would measure the outcomes that they felt were important for their child and their family. This might include aspects of **family quality of life**, an intervention outcome that is often overlooked and that can be difficult to measure.
- We aimed to test this newly developed questionnaire within the **Pre-school Autism Communication Trial (PACT)**, a clinical trial of a communication intervention for young children with ASD and their parents that ran between 2006 and 2010.

Parent Consultation

We ran 5 focus groups with 31 parents of children with ASD. Parents were asked to discuss what they would consider to be the success criteria of a pre-school ASD intervention for their child and family. We analysed the focus group discussion and listed the priorities raised by parents.



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Parental priorities fell into three areas:

- **Changes for themselves as parents**, such as having realistic milestones for their child's development and not having to continually fight for the right support for their child
- **Changes for the child with ASD**. Much emphasis was placed on the child's emotional wellbeing (e.g., being happy and calm) and social integration, such as getting invited to birthday parties and sharing with other children
- **Changes for the whole family**, such as being able to go to family events together and making home routines more manageable. Parents also emphasised the relationship between their autistic child and siblings.



Questionnaire Development

We held a national consultation on the "National Autistic Society" website where we asked parents of young children with ASD to identify how clear the criteria were and which of the criteria were most important. We selected the best items to make the 'Autism Family Experience Questionnaire'.

The **Autism Family Experience Questionnaire** is a 48-item form. Items are worded both positively and negatively and are rated on a 5-point scale (1=always; 5=never).

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Our research is publicly funded and we are committed to maximising the impact of our work. We therefore invite other researchers and practitioners to use the AFEQ. If interested, please discuss with us: Kathy.Leadbitter@manchester.ac.uk

Using the AFEQ within the PACT Trial

- 152 families took part in the PACT Trial. Half of the families in the trial received PACT intervention during the first year of the trial; the other half did not.
- We asked all families to fill in the AFEQ at the start of the trial, one year later (at the end of the trial) and 6 years later (when seen for follow up).
- Parents were able to complete the form easily and said that it made sense to them.
- We looked at the AFEQ data from the PACT trial. We were reassured that the AFEQ was measuring important constructs, as it mapped well onto other well-established measures of child independence and parental wellbeing.
- We found that parents who had received the PACT intervention had significantly better total AFEQ scores at the end of intervention. This relative improvement was still seen 6 years later when the families were seen for follow-up.

Conclusions

- The Autism Family Experience Questionnaire is a tool that can be used to measure the effects of an early autism intervention on the things that matter most to parents. It reflects aspects of family, parental and child wellbeing and quality of life, areas often overlooked within autism research.
- We had already established that the PACT intervention brings about improvements to parent-child interaction and the intensity of the child's autism features. By developing and using this questionnaire we were also able to establish that this intervention has a positive effect on critical aspects of family wellbeing and experience.
- The AFEQ has been published in the Journal of Autism and Developmental Disorders and is free for anyone to use.

