

# Mental Health Psychoeducation for Parents of Children with 22Q11.2 Deletion Syndrome – Feedback and Evaluation

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## Background

22q11.2 Deletion Syndrome (22q11.2DS) is one of the most common microdeletion syndromes (1:2000 to 1:4000 individuals). Usually diagnosed in early childhood the affected children present with diverse range of medical condition and are highly predisposed to behavioural and mental health problems creating high anxiety level among parents<sup>1</sup>.

A dedicated inter-disciplinary paediatric clinic including child psychiatry was established at Crumlin Hospital to address the specific needs of these children and families by providing high quality specialist care. Monthly mental health psychoeducational sessions for parents were introduced as part of the psychiatric input to the clinic.

Psychoeducation is a known tool increasing parents' knowledge and understanding of their children's conditions and informing them about access to services. High quality sessions delivered by professionals also have the potential to build up parents' confidence to deal with commonly seen behavioural and emotional difficulties<sup>2,3</sup>.

## Aims

The aim was to develop psychoeducational sessions tailored to address the main challenges facing the parents of children with 22q11DS, evaluate the feedback obtained after each session and plan future service.

## Methods

A cycle of four psychoeducational sessions was developed covering key stages of children's development:

- Basic principals of parenting and managing common behavioural difficulties – preschool children.
- Managing emotions, anxiety disorders and ADHD in primary school children.
- Anxiety disorders in adolescents, depression and psychosis.
- Transitioning to adulthood and independent living.

One hour session (formal presentation followed by questions and answers) was delivered monthly in conjunction with the paediatric clinic. Parents were also invited via 22q11 Ireland Support Group Coordinator. Anonymous feedback was sought to evaluate the content, delivery, level of satisfaction and perceived level of support using Likert scale questions (range 1 to 5) and free text comments. SPSS 24 software was used for the analysis.

## Results

Two cycles of four sessions sessions were delivered, attended by 25 adults. Informal initial feedback from 7 parents after the first session showed high level of satisfaction. Formal feedback was obtained from 18 attendees at subsequent sessions The sessions met the expectations of 89% (n=16, Mean score 4.3) of the participants. Similarly, the content and the structure were rated highly by the attendees 94% (n=17, Mean Score 4.5). Parents felt supported during the sessions and expressed interest in attending other sessions (94%, n=17). All attendees responded that they would recommend the sessions to others. Some pragmatic difficulties to attend the sessions were raised: child care for the duration of the session, geographical distance, parents' work commitments.

### Comments from parents:

"Very enjoyable and informative."

"Great to receive up to date information."

"Very useful – especially being with other parents."

## Conclusions

This was a pilot study of mental health psycho-educational sessions offered to parents of children with 22q11DS, known to be associated with significant risk of developing mental illness. Overall, the level of satisfaction with the sessions was high. The practical difficulties limiting ongoing attendance as well as the current global pandemic highlighted the need to focus on developing more accessible resources such as online psychoeducational tool kit for carers.

### References:

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