Family Centred Psychoeducation for Families with a Child with Usher Syndrome

Supporting families and professionals through the lens of Self-Determination Theory

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Competence



I am good at what I do. I can achieve my goal.

Autonomy



I can be myself. I make my own choices.



Relatedness



I feel loved, safe and accepted.

Self-Determination Theory

Well-being is supported when the basic psychological needs (autonomy, competence, and relatedness) are satisfied



Training Program for Care Professionals

- Three e-learning modules: 1) Usher syndrome, 2) Autonomy supportive practices, 3) Impact Usher syndrome on life
- Four-hour in-class session to practice autonomy-supportive skills
- Follow-up sessions with experts-by-experience for reflection and learning

Goal:

Strengthen professionals' ability to provide autonomy-supportive care.

Study Design

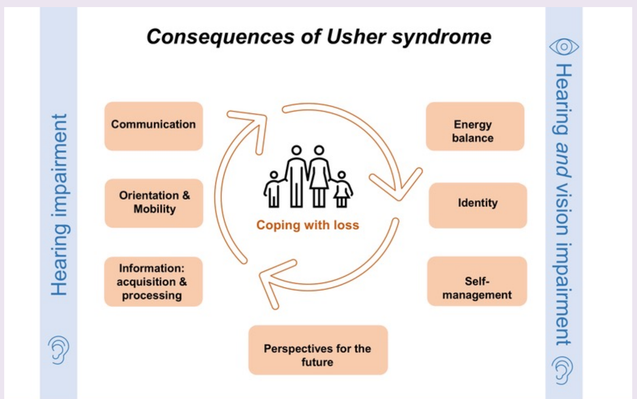
- Single case study
- 26 data collection time points and 3 interviews per participant
- Mixed methods

Participants

- 15 parents
- 1 child
- 11 care professionals
- 8 families with a child with Usher syndrome (aged 1 - 17), from the Netherlands & Belgium

Family Psychoeducation Program

- Includes 8 structured sessions, supported by a manual covering 5 key domains, each accompanied by practical handouts (38 in total). Combined with the training, this forms a ready-to-use package for autonomy supportive care
- Focus on family well-being, basic psychological need satisfaction, and autonomy-supportive parenting



Expected outcomes of the study & future plans

- Insight into the effectiveness of the family psychoeducation program and training program
- Enhanced family well-being
- Follow-up family day in October 2026
- Possible translation of the program into other languages



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Key references
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