

A pilot of a support group program designed for siblings of children with a rare disease or disability in Finland

Background

Siblings of children with a rare disease or disability may be at risk of developing emotional and behavioral problems.

Aim

A pilot to develop a systematic support group program for siblings of children with a rare disease or disability aged 8 to 13 years.

Intervention / method

The pilot consists of once a week group meetings for six weeks in two cities in Finland during 2017. Following a detailed manual, two group leaders facilitates the siblings to:

- strengthen communication with their families and friends,
- explore their own strengths,
- share feelings with others,
- connect with other siblings and
- have a fun experience.

Results

Expected result is significant progress on the GAS. The program works if the siblings will achieve their individual goals. As a universal output, we expect:

- increased communication with their parents,
- siblings become more aware of their own strengths and
- being able to speak up about worries and about disease or disability.

Siblings may be concerned about...



Methods used include parent involvement at the start and at the end of the program.

Goal Attainment Scaling (GAS) will be used to evaluate which individual goals are achieved in the course of the program.

Conclusions

- A sibling's disease or disability affects family's other children, a program is needed to support their well-being.
- The program is goal-oriented and effectiveness is measured with the GAS.
- The program will be enhanced based on the feedback from the participants after the pilot.

