

Development of SIBS-online: An internet-based group intervention for siblings and parents of children with rare disorders

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Background:

Siblings of children with rare disorders have an increased risk of developing psychological problems.

We have developed SIBS, a five-session group intervention for siblings and parents of children with rare disorders (see www.sibs.no).

After participating in SIBS improved parent-child communication, significantly increased wellbeing and diagnostic knowledge in siblings have been reported.

To reach the population of families of children with rare disorders who live geographically dispersed we now develop SIBS in an online format.

Results:

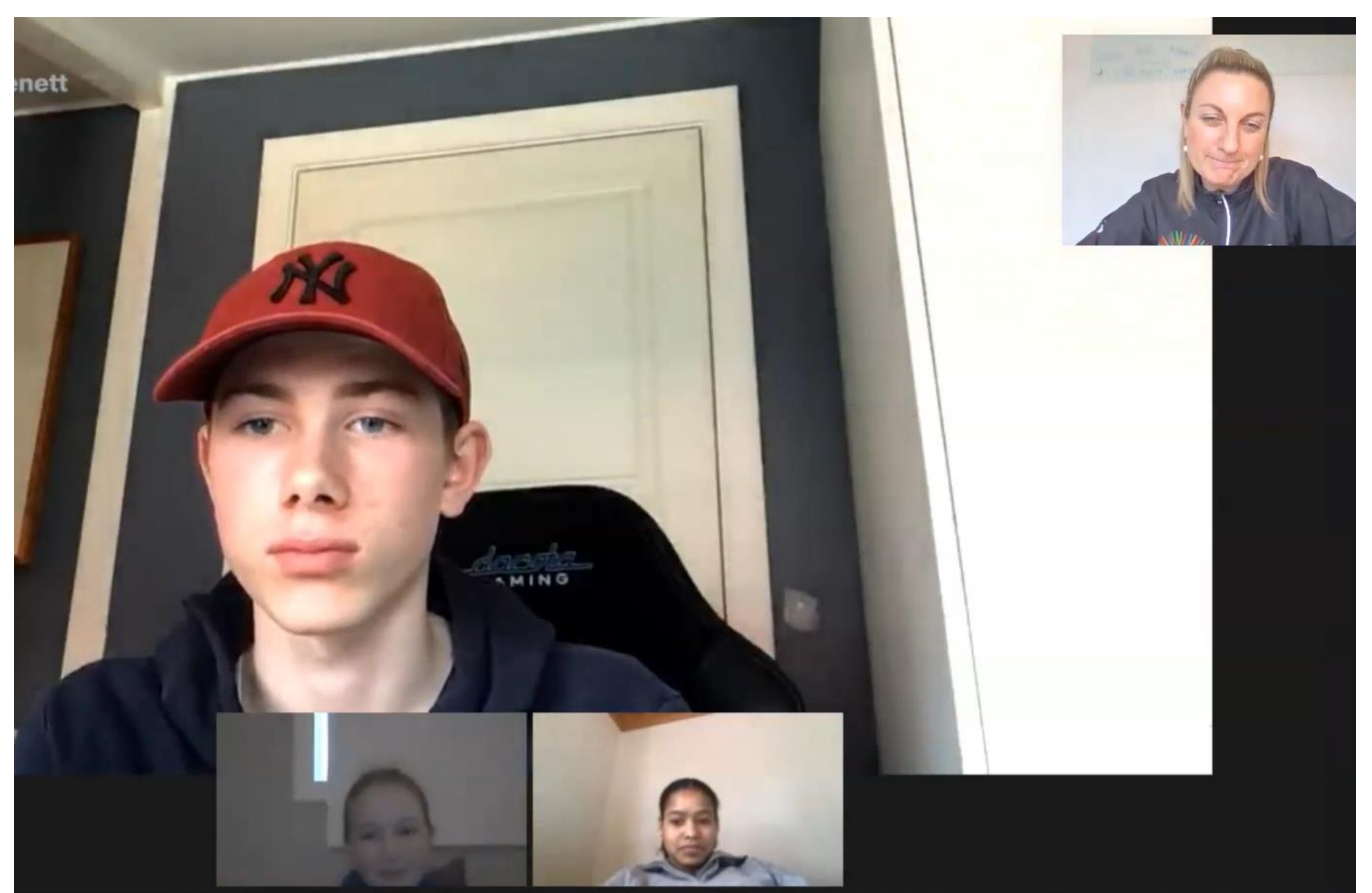
- Siblings experienced the online platform as a *safe place to share experiences*.
- Parents reported the online group to be *easy accessible* in a busy schedule.
- The online format *challenged turn taking*.
- The online format *facilitated identification of prosocial behavior*.
- *Potential structural disturbances* were other people, participant fidgeting, light conditions, and unstable wifi connection.
- Useful group leader techniques were; more direct questioning, repeating participant statements, and circular questioning.

Methods:

To inform the development of the SIBS-online manual, pilot groups with siblings aged 12-16 years and parents were conducted:

- Two general counseling groups for siblings
- Two sibling groups based on SIBS manual
- One parent group based on SIBS manual

Aspects related to the structure (setting & technology) and process (communication & experience) was discussed with participants and documented.



Conclusions:

Participants were positive to SIBS online.

Guidelines about the online setting should be provided to participants in advance.

Rules for communication during sessions should be established early.

Guidelines for actions to take if participants drop out due to emotional distress or technical problems should be developed.

