Sometimes I wish he was not here

The power of exchanging experiences and taboos in group work with parents of young children who have a visual impairment

Knut Brandsborg
clinical psychologist

Statped southeast, Department of vision, Oslo, Norway
knut.brandsborg@statped.no

ECPVI conference, Budapest november 2016
Background

• Working with parents has high priority

• From a transactional point of view: support the parents in meeting the extensive needs of a small child who is growing up without sight in a world made by, and for, people who have sight

• Parent groups, two groups on every parent-child course before school age. Three courses at one of the national centres is offered to all these families before school start
• Participants: six to twelve parents
  Two staff members. One of them a psychologist

• 1.5 to 2 hours in each of two group sessions
Goals – what we want to contribute to

- Give the parents a chance to be seen, listened to, confirmed, taken seriously

- Give them a chance to share thoughts, emotions and experiences with other parents who are «wearing similar shoes», who are on the same side of the wall as they are themselves, where life is different

- Give and receive good suggestions or advice from peers, and from professionals, if they want them
Empowerment: get a chance to have their own competence as parents enhanced

Give them a possibility to build a parental network and to keep up contact after the course is finished
Procedures – how we run a parent group

• The parents have a lot of influence on what topics we will talk about. We have several suggestions based on experience from previous groups
• We tell them the main reasons why we always have parent group work as part of our courses
  - A forum where they can talk about their child or children, but also about how it feels to be them, to be the parents of a «not typical» child
  - A place where the parental expertise and the professional expertise can meet, think together, and learn from each other
  - Assuming that it does not happen very often that they get the chance to share with other parents with some similar experiences, people who know a lot of what this all about without a lot of explanations
• Start off with a round of presentation: «share as much as you like about yourself and your family»
• Do you have any special expectations for this parent-child course? What would you like to know more about when the course is finished?
• Please tell us if there is something on your mind that is important for you to share with the rest of us here
• Requested topics are written down and referred to at the start of the second session. If necessary, a short discussion about priorities is conducted
Recurring themes

• How does it feel to be parents of a child who is «not typical», «has a disability», «is different from the majority»?
• The grief and the pain: what hurts the most right now (if anything)?
• The early experiences: how did it feel then?
• Has there been anything good or positive about it?
• Attitudes and reactions from the social network
• Experiences, good and bad, from meeting the professional support system, kindergarten etc.
• How to respond to comments that may hurt or feel very strange
• How does it feel to meet typical children of the same age, to compare their own child with them?
• How to respond to the child’s wonders or anger or grief about her own visual difference
• Questions and emotional reactions from siblings
• When, about what and how to inform the child and the network about the difference

• Attitudes towards disabilities, handicaps, sensory differences in society. The impact of words and concepts that we use about each other