

«Please, see me»

Siblings of children with a visual impairment

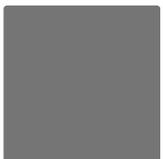
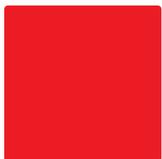
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- What is it like to be a sibling?

What we know

- Problems and challenges
- Positive factors
- What can we do to maximize the positive features?

What we know

- Study by Tøssebro & al (2012): «Like everybody else?»
- On a group level, the big picture: they describe themselves and their lives as ordinary youngsters with some extraordinary experiences
- Most of all it is about ordinary adolescence and ordinary sibling relations
- On an individual level (based on interviews): some vulnerable areas and some resources or advantages
- The parents frequently worried more about the siblings than they did themselves

Two extremes/»ditches» to avoid

- Not to take siblings' worries or problems seriously enough

Too small possibilities for siblings to talk about it

- Take them too seriously with a risk of ascribing too many of their worries and challenges to having a sibling with an impairment. The sibling position may be blamed too much

What can be difficult or challenging?

- Too much responsibility for the care and well-being of their sibling
- Too much responsibility for preventing or repairing hurting comments and behaviour from others
- Too little attention and care

Message from group of siblings to parents:

«Someone with a disability needs more help and care, but not more attention»

- Feelings of embarrassment about sibling

Siblings about responsibility

- «I have probably felt a heavier responsibility than I have been given»
- «I was just about always on guard and felt a responsibility for my brother's well being...even though my parents stated clearly that it was not my responsibility
- «Some of the other siblings I met, told me they had sometimes felt like being at the point of breaking from being helpful»

Siblings about being seen and noticed

- «Sometimes it is unjust that she has the chance to participate in so much. She goes to courses and camps and things. Then I have asked myself if I would have preferred to be blind, but after all I prefer seeing her go away to courses»
- «When she lost her sight, Mom got so desperate that she went away for a while. At that time i just couldn't be mean, I was only sad and quiet.»
- «My achievements are taken for granted. My brother's achievements are always considered exceptional»

Or....?

Should I be good, kind and dumb
Patted on the head and forgotten

Or

Should I be mean, impossible and angry
And get an hour

Alone with Mom in the kitchen

Or.....?

Sister about jealousy

- Sister 20 years: «Yes, i was very jealous, but somehow it was never directed towards my sister, but towards Mom. No matter how jealous, mad and bitter and everthing I was, it was never directed towards my sister.»

Positive features

Tøssebro & al:

- On the average: a closer relationship with the parents
- A sense of solidarity in the family, «this is a joint task»
- Solidarity with a sibling who is particularly vulnerable in a social sense, partly because I am in the same boat
- Higher score on autonomy and the ability to care for others
- Higher score on values like equality and diversity

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- «It is not a positive situation to be the big brother of someone who is blind and has profound additional disabilities, but it may lead to good things»
 - «Perhaps I have a better understanding of some things than many of my peers?»
 - «Difficult and challenging. Really cool and very proud»
 - «I have learned a lot about what it is like to view the world in a somewhat different way»

To be important and valuable by being useful

- Adult sister: «I know that I was useful. Frequently Mom said that «had it not been for you when the going was toughest, we would never have made it.....»
I think she really meant it»

Possible signs of concern

- A lot of aggressive behaviour or challenging ways of getting attention or contact
- If a sibling is so self-sacrificial that he/she does not have time for a life outside the family
- If a sibling spends just all about all of the time outside of the family
- Long lasting sleep problems
- A lot of bodily «aches» without reasonable medical explanation
- Longer periods of regression in development

What can be done?

- Contribute to the sibling's feeling of self esteem: «I am good enough as I am.»
- Inform siblings about the disability and its consequences and ask for their advice and opinions
- A father: «We who are parents easily forget to involve younger siblings in what is going on, in the way we do with the older ones»

«I think we should be very direct when it comes to talking about the disability. A sibling may well be given information without having to take part in the parental responsibilities»

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- Frambu Health Center: «Our experience is that siblings show great strength when they are informed and included in what is happening»
 - Information may contribute to prevent insecurities like these (with particular relevance to young siblings)
 - «Do they go away so often with my brother, and without me, because I have been bad?»
 - «Do they love him more, is that why they spend so much more time with him?»
 - «Is it my fault that he is blind, or that Mom and Dad are sad?»

What can be done

Responsibility

- Advice from sibling to sibling:
Use the «pause button»
Take the risk and use the terrible «No-word»

Getting time and being seen

- Give «ear marked» time alone with one of the parents on a regular basis

Information

- Perhaps give some information, in writing or verbally, to sibling's network?

Allow and acknowledge feelings

- Make a large room for strong feelings, including the ones that are not considered proper or correct
 - «Feelings are always true, for the one who has them»
 - «What is most important is not what feelings we have, but how we handle them»
 - «My head may understand why my sibling needs more care and attention than I do, but what does my heart say....?»
- Said by the father of a multiply disabled child
 - «Our children are allowed all kinds of feelings.... including that they sometimes wish their disabled sibling dead....it does not make it simpler when we know by ourselves that we, too, have had that wish sometimes....»

Young adult sister about feelings

- «Looking back, it feels like I had twice as much reason to be jealous than most siblings, but only half the right to show it»

Try to make «openings»

- «Maybe it's not always so easy to be A's sister...?»
- Perhaps you have experienced people saying bad things or asking strange questions about A....?
What happened then?»
- «I heard about another little brother the other day.
He had said that.....»
- Young children: ask for a drawing of the family and comment on it
- Read a book, watch a movie about this theme together
- Look out for and receive «test balloons»

Someone to talk with (for some, not all)

- About contradictory or taboo feelings
- About comments from others
- About the future: what happens when I am an adult and my parents are dead

- Not necessarily always the parent who are in the best position to listen to and contain questions like these
- Another person in the family, a school counsellor or teacher, someone I have confidence in, one who has time and heart to listen to me and accept my feelings

Meeting other siblings

- «It is easier to open up when you know that the other ones have experienced something similar and have an understanding of it coming from the inside»
- Older siblings: organized sibling groups, preferably with an adult present who has had somewhat similar experiences