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Groups for siblings of children with Down syndrome

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Abstract

This article is an exploration of accounts given to us by children who have siblings with Down syndrome. At regular get-togethers organized by the FCSD these children are afforded an opportunity to discuss and share their experience of having a brother or sister with a disability.

The article examines the aims and dynamic of these groups and exemplifies the feelings expressed by the children. We shall endeavor to understand and attach meaning to their experiences and emotions by referring to quotes taken from various sessions.

Keywords. Siblings with Down syndrome. Groups for children. Meeting space. Fraternal relationship. Feelings expressed.

Introduction

The Fundació Catalana Síndrome de Down (FCSD) has for several years been running groups for children who have a sibling with Down syndrome (DS).

We believe it is vital to devote time to these children as at home they are often overlooked. With all the best intentions of enhancing quality of life for their child with DS, parents focus most of their energies on her, at times perhaps failing to realize that their other children also go through and are affected by the disability. It is not uncommon for parents to overprotect the child with a disability whilst also overestimating the capabilities (cognitive and emotional) of the child without a disability, ignoring any issues she may have. In the main, studies have tended to conclude that children who have a sibling with a disability endure more stress and are therefore more at risk of mental health problems. Notwithstanding, not all siblings of a child with DS are bothered by her and, very often, they live happily together. Every child is unique and every family has its own way to solve conflicts. In addition to individual personalities, other factors are at play when it comes to how the family deals with having a child or sibling with a disability. Such factors may include the number of children in the family, the age and sex of the child with a disability, the order of birth, and the age interval between each sibling.

In an effort to understand and respond to each family and every child who has a sibling with DS, we provide this specific meeting space.

Group aims and dynamic

Aims of the meetings

1. Getting to know other children who have a sibling with DS

All children (and all adults) need to know that there are other people in the same boat as them. A child who has a brother or sister with DS is very probably alone in this respect in their class, neighborhood and immediate environment. Many such children think their plight is unique and this makes them feel like the odd one out. Being able to meet other such siblings and spend time with them is both a relief and a comfort.

2. Learning about DS and the FCSD

Siblings usually have hazy ideas to be clarified and questions to ask on issues pertaining to DS.

Some of these issues are very straightforward and the child simply does not know whom to ask. They may be embarrassed to talk to their parents or want to protect them from the pain of discussing the topic. But whatever the reason, these children are all too often grappling on they own with vexing questions. One of the aims of these meetings is to provide age-appropriate answers to these doubts.

In addition, most of the children who come to the meetings know that their brother or sister comes to the FCSD, but not what they actually do there. Explaining the various services offered by the FCSD and the way we understand disability and help people with DS is extremely important information which often clears up many of the siblings' unresolved issues.

3. Being able to express and identify feelings

Everybody needs to talk about their feelings. For many children this is frequently the first time they have been able to talk about their brother or sister and about how they feel as part of the family. They can also discuss and reflect upon what it is like to have a sibling with DS at school, around their friends, on the street, and so forth. In the home these topics are often taboo for the reasons given above.

4. Sharing experiences and helping each other out

Being able to listen to other stories - in this case from children who are all in similar situations - is extremely enriching. Another advantage is that the children can build on their own experience to help each other out and to come up with ideas and solutions.

Group dynamics

We run two groups aimed at 5- to 16-year-olds which are split according to age (5-10 and 11-16). The participants are offered three 90-minute sessions led by two therapists, with group sizes ranging from 4 to 10 children.

Each session may include a range of activities: information, Q&A, work using photos, videos and stories, time for thought, and play.

When the course of sessions comes to an end, a meeting is held with the parents during which the therapists discuss the most important issues that have arisen in the group and the activities that they have done. With a view to respecting the children's privacy, all references made are general and no specific individuals named. Parents are also invited to put forward comments and opinions, albeit without specifically discussing their own child. Should they wish to do this, one-to-one interviews with the therapist can be arranged.

Feelings expressed in the group

Sibling relationships have an enormous bearing on our lives. Brothers and sisters share experiences that they will not share with anyone else. The fraternal relationship between a child without a disability and a child with a disability is special. However, as has already been mentioned, every child is unique and goes through their own experience of having a sibling with DS.

Notwithstanding these individual differences, we have observed in these group sessions that certain feelings and experiences are common to most children.

Not all of the feelings present in the fraternal bond are negative. Many children do describe times of happiness, complicity and affection, though the most frequently mentioned feelings are:

1. Mixed feelings

Having mixed feelings (love/anger, tenderness/rejection, admiration/shame, etc.) about our loved ones (parents, friends, siblings, etc.) is a fact of human nature and must be accepted as such. However, when a sibling with DS is concerned, the plot thickens somewhat. We have found that some children are reluctant to express negative feelings towards their sibling with a disability and that they are therefore in denial of these feelings. It is striking to see that when asked what they like least about their brother or sister, some children will reply, “Nothing, I like everything,” and yet they go on to describe experiences charged with anger. Being mindful of these mixed feelings and being able to discuss both the negative and the positive without feeling guilty is vital.

Some children do find it possible to express such feelings. An 8-year-old girl, in reference to her 10-year-old brother, said: “The thing I like most about my brother is that he's nice and funny, and the thing I like least is when he gets angry about everything and shouts.” For one 13-year-old boy, “I like it when my brother laughs and is happy, but I don't like it when he's naughty and he

doesn't get told off."

In the book «El meu germà Pol» ('My brother Pol'), 12-year-old Mercè describes her brother with DS as follows: "My mum complains about it a lot and says everyone thinks people with Down syndrome are really sweet but her boy is the exception, and then she sighs. It's not that he isn't sweet, but he's also cheeky and stubborn and he has tantrums. And he can be really, really annoying. The fact is, whatever your intelligence, everyone has a good and a bad side."

2. Guilt

We have also observed that parents are generally unwilling to allow their other children to express negative feelings towards the sibling with a disability. As a result, these feelings are denied and the child feels cut off, being forced to hide her real feelings in addition to feeling guilty for being a 'bad' brother or sister. Having the opportunity to express negative emotions (which exist in all fraternal relationships) helps the child to feel good about herself.

Some siblings feel guilty when they compare their own abilities to those of the child with a disability. Their guilt is linked to being the 'healthy child' or to overtaking their sibling. This is frequently seen in children who are younger than the sibling with DS as they begin to realize they can do things that their older brother or sister still cannot. In the words of a 6-year-old girl, "I don't understand why my brother who's 9 writes so badly because I'm only in my first year at primary school and I can do joined up writing." For another boy of 7: "My big brother won't ride his bike with me because he doesn't know how to, but I like it and I don't need stabilizers anymore."

On a related note, one mother reported that despite her 13-month daughter being ready to start walking, she did not eventually do it until her 26-month sister with DS began. "She waited for her," said the mother.

3. Injustice

Most of the children believes they do not receive equal treatment from their parents as the sibling with DS. Many notice that the parents struggle to set limits on the child with a disability. This gives rise to a common sense of injustice when boundaries are being set. As one boy, aged 11, angrily related: "I always get the blame and if I ever complain about it my mum says that 'He doesn't know what he's doing and you do.'" A 9-year-old girl told us, "When we're at the table I always get the blame because of him and it's not fair!"

The children describe how the sibling with a disability is mollycoddled whilst an unequal and unfair degree of responsibility is demanded of the other brothers and sisters.

For one 10-year-old boy, "My brother, who's 12, never does anything and I always have to set the table."

4. Shame

Shame is a feeling that often rears its head when we come under scrutiny from others. A 12-year-old girl described it thus: "I feel really embarrassed when my friends come round and ask me what's wrong with my little sister." A girl aged 7 said: "The other day in the park some kids started to laugh at my brother and say he was stupid, and I was really embarrassed."

Many children will stand up for their sibling when they perceive mockery. Such is the case of one 9-year-old boy: "One day in the playground some kids were making fun of my sister so I went over and called them names."

Frequently, it is not only appearance but inappropriate behavior that makes children ashamed of their sibling. As one 10-year-old girl put it: "One day on our way to the Foundation we were going up the stairs and my brother farted, and a lady stared at us and I was really embarrassed."

It is interesting to note that in the home certain acts can be perceived as amusing whilst in public the same behavior causes shame. In the words of one girl, aged 6: "What I really like about my brother is that he messes around when we're having dinner at home and it's really funny." However, the same girl later said: "It's really embarrassing when we eat out because my brother eats like a pig and burps."

Some final considerations

At the end of the 3-session course the children and therapists get together to discuss their opinions and level of satisfaction about the meetings. For the overwhelming majority of children, the experience is extremely positive. These meetings have knock-on positive effects on the family also. In later meetings many parents tell us that their

children have changed as a result of the get-togethers. For instance, they are closer to and more affectionate with their siblings and are more open and communicative, broaching issues they had never mentioned before.

Although such a short space of time (only three sessions) does not entirely constitute psychotherapeutic treatment, both the work done and the results achieved are therapeutic and highly beneficial for the children and the parents.

In light of the interest in and satisfaction with these courses, the FCSD is planning to enlarge the groups and open new groups for teenagers and adults. We feel it is important for older siblings also to have this opportunity for encounter, talk and reflection. This will reveal how the feelings expressed by children develop in later stages of life.

Bibliography

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News

Fundació Catalana Síndrome de Down will be holding its 10th International Conference on Down Syndrome as well as celebrating its 25^th anniversary on 12 and 13 November 2009. The title of this year's edition is "Conquering Dignity", and the topics, to be addressed from a bioethical perspective, will be the stages in the life of a person with Down syndrome from birth through neurological development and early stimulation, followed by schooling and employment, and emancipation from the parental home. Issues considered will include matters of identity, respect, and the support required by individuals with Down syndrome in planning and making their own lives, as well as their contributions to society, societal attitudes to disability, the relationship between families and professionals, and a number of other points geared to learning more about the present state of things, taking on new challenges, and tackling the emerging needs arising as a result of increased life expectancy in this population group.