



Understanding Chromosome & Gene Disorders

Supporting Siblings of Children with a Rare Genetic Condition



rarechromo.org

The Sibling Relationship

Siblings play an important role in children's learning and development. Interactions with brothers and sisters provide opportunities to learn about sharing and emotional reciprocity, to develop social skills, to express thoughts and feelings, and to practise resolving conflict. But for children whose brother or sister has a disability, such as a rare chromosome disorder, some of these sibling experiences may be different.

Many parents worry about how their non-disabled child will be affected by the experience of living with a brother or sister with a disability, and a great deal of research has explored both the possible negative consequences and also the potential benefits for siblings. In this article, we summarise the research findings and provide suggestions for ways that parents can support the positive development and well-being of all their children.



Research about Siblings of Children with a Disability

Sibling research has been undertaken with families of children affected by different kinds of developmental disabilities and chronic illnesses. Generally, the focus has been on more common disabilities such as Down syndrome, autism and cerebral palsy, and childhood illnesses such as leukaemia. As far as we know, there has been no research specifically about siblings of children with a rare chromosome disorder, but it is likely that these siblings share many common experiences. Siblings of a child with a rare chromosome disorder may also have to deal with some unique issues because of the rarity of their brother or sister's chromosome abnormality, and the limited information that is likely to be available about developmental consequences and prognosis.

Overall, the research provides mixed, and sometimes contradictory results about the effects on siblings, and this is at least partly because of differences across studies. They vary in the type of disability involved, and many other aspects that can impact on the sibling experience, such as children's ages, family income, family structure (two parent, single parent or extended family), and sibling order (whether the child with the disability is older or younger than the sibling). It seems that outcomes for siblings depend on a range of factors including the care and medical needs of the child with a disability, the amount and type of support available to the family, and the parents' own ability to cope. Although some studies have concluded that siblings of children with a disability are no different to others, most research has tended to report the potential for both negative effects, such as emotional or behavioural problems, as well as positive ones, such as increased compassion and personal growth.

Challenges for Siblings

Siblings of children with a disability face a particular set of challenges. Financial and time pressures in the family mean that they may have fewer opportunities for engaging in social or community activities, family outings and holidays.

Parental attention may, at times, be focused more on the needs of the child with a disability, and there may be high levels of stress within the family. Siblings can experience difficult emotions and feelings about their brother or sister and the family situation. Feelings of guilt, grief, confusion and anger are not unusual. Siblings may be afraid to tell their parents how they are feeling, or they may worry about adding to the difficulties and stress already faced by their parents.

One of the challenges that is particularly relevant to rare chromosome disorders is information. Like parents, siblings generally want to know the causes and possible consequences of their brother or sister's chromosome abnormality.

They may worry about the possible implications for their own health and that of their future children. Siblings may not receive enough information or they may find it impossible to understand. Genetic testing, if it occurs, may be stressful and confusing for them. Roles and responsibilities can also be challenging for siblings. Expectations for self-care and care for their brother or sister may sometimes be beyond what is usually considered appropriate for their age.

In combination, these challenges have the potential to impact negatively on a child's social and emotional well-being. The reverse, however, is also true.

Siblings often report positive experiences and psychological growth because of their exposure to these challenges.

Positive Outcomes

One of the relatively consistent research findings is that siblings of a child with a disability tend to develop more compassion and empathy for people, and a greater level of tolerance and acceptance of differences. Comparisons with children from families not affected by disability suggest that many siblings achieve higher levels of social competence, demonstrating maturity, self-control, reliability, responsibility and self-confidence, as well as developing a stronger appreciation of life and good health, and an enjoyment of simple pleasures. Research has shown that siblings can develop a very close relationship with their brother or sister with a disability, becoming actively involved in their care and support, and celebrating their progress and achievements.

Negative Outcomes

At times siblings may experience high levels of anxiety or worries that they are unable to share, or they may "act out" in anger, resentment or frustration at their sibling or others. These two kinds of responses are known as "internalising" and "externalising" behaviours, respectively. Such responses are not unusual when people feel marginalised, face chronic stress, or believe they have little control over their environment. Because of limited participation in

social or community activities, or embarrassment when friends visit, siblings may have difficulty forming and maintaining friendships. Some also experience academic problems. Family stress may make it difficult for siblings to study at home or pay attention at school. Alternatively, they may try to downplay their own academic successes or they may become compulsive over-achievers.

Indicators of Stress

There are signs parents can watch for which indicate that a sibling may be experiencing stress. These signs include withdrawing from family, friends or usual activities; behaving disruptively or aggressively; and being an obsessively “good child” or “people pleaser” who denies or ignores their own needs to look after others. Some siblings may struggle with perfectionism and overachieving, thinking that they need to compensate for their brother or sister’s limitations. The resulting fear of failure can make them seem anxious and depressed, or they may say things that suggest they do not value or like themselves very much. Problems such as stomach-aches, headaches or insomnia may result from difficult or conflicting feelings and emotions, rather than physical sickness. Potentially, all of these signs can indicate that a sibling needs some additional support to help them cope more positively.

Supporting Siblings

It is common for parents to receive many well-meaning suggestions and advice for how they should help siblings to cope. We focus here on the types of support that research has identified as being effective for enhancing the well-being of siblings.

Feelings

One of the most important things you can do is to allow siblings to express their feelings. They may be struggling with ambivalent emotions or ones that are complex and difficult for them to deal with. Research has shown that siblings are often confused by conflicting feelings – for example, they may simultaneously feel both protective and resentful of their brother or sister. Give them the opportunity to talk about how they are feeling, and share some of your own feelings. Acknowledge that negative emotions are understandable, and that it is perfectly normal at times to feel embarrassed or angry or worried. It is important to let children know that it is still OK to have fun and do normal things, even if their brother or sister has a serious condition.

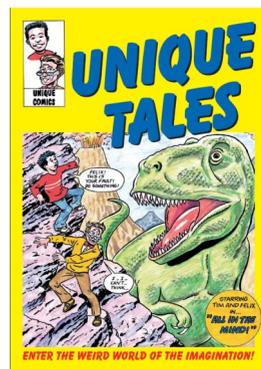
By allowing siblings to talk about their emotions, you are acknowledging them, you are showing that you care and you are reinforcing that they can come to you to discuss their problems. This is particularly important because some siblings report feeling lonely or isolated from their parents. Making time to talk to siblings about their feelings allows them to feel they are a valued part of the family and that their needs are heard.

Information

Another important thing you can do is to provide honest, accurate information so

that siblings do not develop irrational beliefs or fears about their brother or sister's chromosome disorder. Some parents may withhold information because they want to protect siblings, and it can often be difficult to know what to say, especially when the progression and long term outcomes of the disorder are unknown or uncertain, as is often the case for rare chromosome abnormalities. When sharing what is known about the disability, remember to talk not only about the affected child, but also about the likely impact on other family members. Acknowledge the frustration you feel about the limited information and things you do not know. If the sibling is undergoing genetic testing, provide sufficient information about the process in advance, at a level appropriate for the his or her age. Afterwards explain the results clearly so that misunderstandings do not occur. Older siblings may benefit from access to genetic counselling, especially if there are likely to be implications for their future children.

When talking about the rare chromosome disorder with siblings, make sure that you give information that is appropriate for their age, use clear language with sufficient detail, and repeat information more than once to help the child to understand as fully as possible. The *Unique comic book* (*Unique Tales* available from *Unique* or from *Unique's* website, www.rarechromo.org) is an ideal way for children to learn the basics of genetics. Encourage siblings to ask questions and check back with them to make sure that they have understood the information. You may need to be prepared to discuss difficult topics about what the future could hold for their brother or sister.



It can also be very helpful to discuss how siblings might explain their brother or sister's condition to others such as their friends. This can be particularly challenging because of the fact that most rare chromosome disorders do not even have a proper name! Together with the sibling you might prepare some clearly worded information and then practise it in role plays. Try to present the information in a positive way. For instance, you might encourage the sibling to begin by saying "Well, it's so amazing that my brother has this incredibly rare set of chromosomes – they say he's probably the only person in the world like this – isn't that totally awesome!" or "It's incredible how many fascinating things can happen to your chromosomes" or "Well, you mightn't realise when you just look at her but in most ways she's just like other kids". These examples illustrate ways you could re-frame potentially negative information about a child's disability much more positively.

Family Routines and Responsibilities

Another family factor that is important is the establishment of routines and responsibilities for each family member. Regular and predictable family routines can help siblings to feel more secure in their daily lives, especially if

you include some regular leisure activities and opportunities for a parent to spend special time alone with the sibling. Although it can often be difficult to adhere to such routines because of unexpected family events and crises, even a brief amount of regular one-on-one time with a sibling can be valuable. In addition, siblings need to have the opportunity of spending time alone, and to have their own space and privacy when they need it.

Try to include siblings in family routines related to their brother or sister's care, and respect their choices about the extent to which they want to be involved. If siblings are happy to be included, ensure they do not take on too much responsibility. Many older siblings indicate a desire to participate in appointments with professionals and in decision-making. Of course, this needs to be considered in relation to their age and level of maturity but, in general, allowing involvement can decrease the sense of helplessness that siblings sometimes feel about their role. You can help by letting them know they are valued, and acknowledging the special role they play within your family.

Research has reported that siblings often complain about unequal division of household chores, a complaint that seems to be common across all families, not just those in which one child has a disability! However, it is important to share tasks as equitably as possible and not overload siblings with responsibilities at home. Focus on what your child with a rare chromosome disorder is able to do, and provide opportunities for her or him to be responsible for some simple household chores if possible. Your family is likely to function more happily if you can keep rules and responsibilities as fair as possible, without appearing to favour or make unnecessary allowances for one child. Your child with a rare chromosome disorder will benefit too from routine. When given regular chores like other family members, he or she is likely to feel a stronger sense of belonging in the family and heightened feelings of self-efficacy when tasks are achieved. If families have regular routines, all family members tend to feel more in control, and more able to cope when crises do occur.

Support from outside the family

While parents are able to seek help from doctors, therapists, books, websites and parent groups, siblings tend to rely solely on their parents for information and support. Sibling support programs are now widely available in many countries, including the UK, USA and Australia. These programs aim to buffer the effects of stress and help siblings to cope and function better by providing a supportive, non-judgemental environment with opportunities for positive interactions with peers and trained adults such as youth workers. Siblings of children with disabilities come together (for example, in workshops, holiday camps or online chat rooms) to share their experiences of living with a brother or sister with a disability. They are encouraged to express their emotions freely and safely with others who are likely to understand and empathise because of their own unique experiences as siblings.

Scientific evaluations, although not frequently undertaken, show mixed evidence for the effectiveness of sibling programs. However, positive benefits have been noted, including increased knowledge about disability, more positive coping strategies, and pleasurable recreational opportunities that might not otherwise have been possible. Not every sibling will benefit from group programs, and some will not enjoy interacting with other siblings in this way.

An alternative for support outside the family is professional help from a psychologist. For siblings who are obviously not coping well, or for those who are showing some of the warning signs mentioned above, professional help can be valuable. Some siblings may appreciate being able to discuss their worries and concerns with someone who they perceive to be neutral and objective. You should stress to your child that consulting a professional does not mean that there is something wrong with them; rather, it should be seen as a positive way of taking responsibility for improving their own well-being. Psychologists can help siblings to develop skills and strategies for dealing with difficult, stressful, frightening or embarrassing situations, emotions and thoughts.

It can be useful also to engage school support and understanding for siblings. At various times, siblings may be distressed or disruptive at school, or they may not perform their best because of stress or worry. Some siblings may experience bullying or teasing about their brother or sister that will need to be addressed by the school. Providing teachers with accurate knowledge about the situation will enable them to be more flexible, understanding and supportive of the needs of siblings.

Conclusions

Being the sibling of a child with a rare chromosome disorder can bring challenges. Although many will at some stage experience stress and negative emotions, research has generally shown that most siblings cope fairly well most of the time. Indeed, many not only cope, but also thrive, developing valued personal qualities such as empathy and tolerance.

Children who have a rare chromosome disorder usually need a lot of support and attention from their parents, but it is important that siblings are not overlooked as a special part of the family too. Parents can support siblings by being aware of the challenges they face, listening to their concerns and feelings, providing information about the chromosome disorder, developing family routines, and enabling access to supports such as sibling programs and psychology services.

Finally, remember that all families are different and all children are different. Some siblings cope better than others. Some may thrive, while others may need considerable support to ensure their well-being. Overall it seems that, despite everyday difficulties and occasional crises, the sibling relationship is amazingly resilient, in some cases becoming even stronger when one child has a disability.

Inform Network Support



Understanding Chromosome & Gene Disorders

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Useful Websites

www.siblingsupport.org
www.sibs.org.uk
www.siblingsaustralia.org.au

Unique mentions other organisations' message boards and websites to help families looking for information. This does not imply that we endorse their content or have any responsibility for it.

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