

# Supporting Siblings

When a Brother or Sister has a Disability or Chronic Illness



Association for Children with a Disability

• Information • Support • Advocacy



# Association for Children with a Disability

The Association provides information, support and advocacy to families who have a child with any type of disability. Our Parent Support Workers and our Committee of Management are parents of children with a disability. We also work in close co-operation with a network of Regional Parent Support Co-ordinators in Victoria and various statewide and national parent support groups, including the Australian Association for Families of Children with Disability. For families we provide free telephone information and advice about any issues relating to children with a disability including education, respite, aids and equipment, home care and recreation. Our contact details are:

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## Keeping up-to-date

One of the best ways to keep up-to-date with new programs and services is to become a member of our Association and read our bi-monthly magazine, 'NoticeBoard'.

Membership costs only \$5 or \$10 per year for families and \$25 for organisations.

See the application form on the back cover of this booklet or contact our office on (03) 9500 1232 or 1800 654 013.



'NoticeBoard' includes family stories, real life accounts about what life is like for families of children with a disability. They are a timely reminder that you are not alone and share similar experiences with many other families.

We also distribute the free booklets

'Helping You and Your Family: Self-help Strategies for Parents of Children with a Disability' and 'Through the Maze: A Guide to Benefits and Services for Families of Children with a Disability.'



Most of our members are parents of children with a disability, but family and friends, students, professionals and service providers are also welcome to join and enjoy the benefits of receiving 'NoticeBoard'.

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## 'Supporting Siblings'

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People and organisations are free to copy and distribute this report to assist families of children with a disability as long as appropriate formal acknowledgement of the source is provided.

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# The Siblings Project at the Association for Children with a Disability

Since April 2002, the Siblings team at the Association has been developing resources to support brothers and sisters of children with a disability or chronic illness. These include:

- A [Siblings Program Directory](#) that lists over 30 programs across Victoria, see [www.acd.org.au](http://www.acd.org.au). You will find a description of what the program offers to young people, costs and eligibility criteria.
- [Supporting Siblings Information Sessions](#) for parents and service providers working with families who have a child with a disability, in all regions of Victoria. Contact the Association on (03) 9500 1232 or 1800 654 013 (rural callers only).
- Your Shout at [www.yourshout.org.au](http://www.yourshout.org.au) is a web site created by adolescent siblings with a brother or sister with a disability or chronic illness. It is a place where young people can express their views and connect with other young people who might share their experience.



# Introduction

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As an adult sibling with a brother who has autism and a severe intellectual disability, I have thought a lot about the ways my family and I coped as we were growing up. My parents listed the things that would have helped them cope better, which included knowing what to expect for their children without the disability. Looking back on those years, I believe that our individual ability to cope was influenced by the capacity of our broader community to support us.

Australian researcher, Monica Cuskelly, advocates for longitudinal and cross sectional research into outcomes for siblings and to consider factors such as culture, family dynamics and coping strategies used within the family. <sup>1</sup> Such research may help service providers to identify what types of support are most effective for specific groups.

Siblings of children with a disability or chronic illness may not feel able to express their concerns and needs to their parents and may lack the opportunity to give expression to their feelings, hopes and fears. The aim of this report is to outline what current research tells us about sibling experiences and thereby help parents to reflect on, and understand, their children's experience of growing up with a brother or sister with a disability or chronic illness.

This report is divided into two sections:

## **Section 1: Sibling Experiences from Childhood to Adolescence**

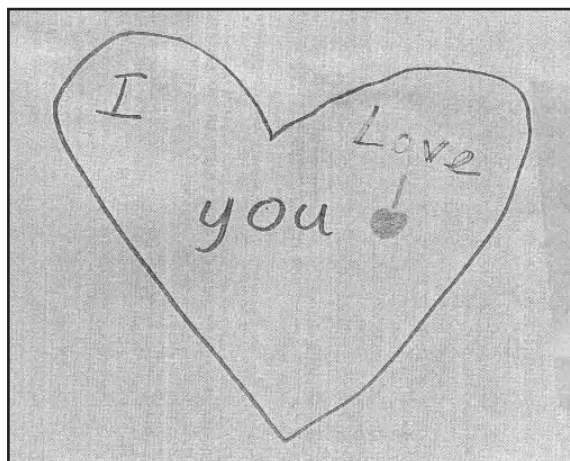
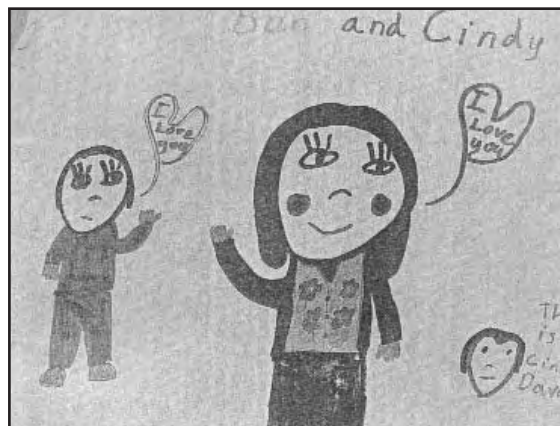
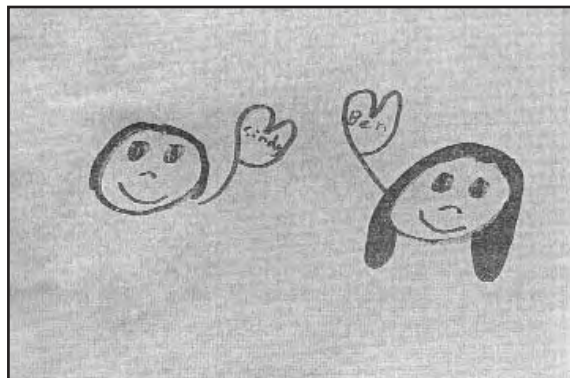
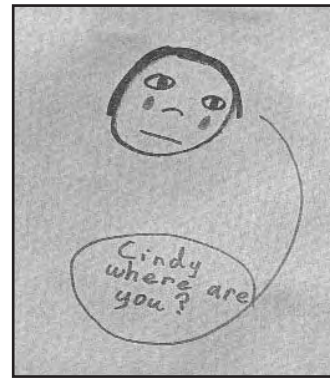
Considers how siblings respond emotionally, and with their behaviour, to growing up with a brother or sister with a disability or chronic illness. These responses are described within the context of the stages of child development from infancy through to the teenage years.

## **Section 2: Family and Social Influences on Sibling Adjustment**

Explores sibling experiences within the context of the family and social environment.

We hope that this dual focus on both the emotional responses of siblings at different stages of development and sibling experiences within the family and social environment, will provide an opportunity for parents to reflect on ways to best support siblings.

**Miranda Smith**  
**Siblings Project Worker**  
**Association for Children with a Disability**



# **Section 1**

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**Sibling Experiences  
from Childhood to Adolescence**

# Sibling Experiences

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"I asked Youssef, my three year old, if he wondered why Sarah was different. He replied "what Sarah different?" So I tried to explain the differences to him, knowing full well he wouldn't understand. I explained to him about the facial features. He told me "No! Sarah is like me!".

Inside I smiled and knew his heart will be big enough for the two of us. I then explained to him why Sarah was in hospital Wednesday night. He said, "I'm sick like Sarah. Take me doctor". I did take him and the doctor was really good at playing the game. I then asked Youssef if he understood everything I had said. He said "Yes, Sarah and Catty (the cat) I love them". I know when he is ready to understand he will ask me but it will be in a couple of years. I just hope that he will still be able to say, "Sarah is like me". " <sup>2</sup>

A sibling's response to growing up in a family that has a child with a disability needs to be understood in the context of their stage of development. Children respond to the events of day-to-day life based on their stage of physical, mental and emotional development. Consider a seven-year-old's self-centred view of their sibling compared to a fifteen-year-old's empathic response. Likewise, a nine-year-old's perspective, sensitivities and vulnerability will change, as she or he becomes an adolescent.

Children learn from their environment and (most importantly) through their relationships with their parents and siblings. The sibling relationship, which is life long, has an important influence on the development of a person's identity. In later life, it can be a source of mutual support, depending on the quality of the early relationship.

With the birth of a child with a disability, families find themselves in unfamiliar circumstances. In order to cope, families begin a process of change and adjustment. Within the literature on sibling experiences, themes of conflicting emotional responses emerge; therefore, sibling adjustment can be considered in terms of managing the influx of strong and conflicting emotions.



# The Sibling Relationship

"We see Erika feel sad and rejected when Thomas pushes her away. We see her try to make sense of it all when she looks at us and says, "Thomas not talk, Mommy." <sup>3</sup>

There are many features of the sibling relationship that distinguish it from that of parents, grandparents, aunts or uncles:

- The sibling relationship, extending from childhood through to adulthood, will usually be longer than any other relationship within the family.
- From birth throughout the formative years, a child's self identity is shaped by their daily interaction with their sibling/s.
- Young siblings are prone to feeling responsible for their sibling's and their parents' well-being. They witness first hand the difficulties those closest to them are experiencing.

For the sibling of a child with a disability or chronic illness, other factors that are not common to the sibling relationship come into play:

- A sense of responsibility for their sibling beyond that felt by their peers. Depending on the degree of their sibling's disability or illness, they may assume guardianship for their sibling when their parents die.
- For siblings of children with communication difficulties, the normal 'give and take' in a relationship may not exist. For example, a child who is interacting with their sibling with autism will come to understand that you don't always 'get what you give'.
- Ongoing family circumstances that give rise to feelings of anxiety for themselves, their sibling and other family members.
- Siblings may begin to experience feelings of grief and loss as they become aware of the meaning of their brother or sister's disability or chronic illness and its impact on both the child with the disability and themselves in the future.

# Forming an Identity

**"When she was about two, she started to pull on me (just as Thomas does to communicate with us). At first I resisted going with her. She is normal. She does not have to communicate this way. It represented too many issues for me, but then I realised this was her normal. I followed her around for two weeks. Then slowly she realised she didn't have to communicate that way. But she needed to know I would respond to her in the same way as I did to Thomas, that she was just as important." <sup>4</sup>**

Younger siblings learn by watching and imitating older siblings. Developing a 'pretend' disability can be a young child's way of imitating the behaviours of their sibling, which they perceive as getting attention from their parents.

**"Hi! My name is Lydia and I am eight years old. I have a brother and his name is Trevor. He is special because he is retarded. And I am special too because I am cross-eyed sometimes." <sup>5</sup>**

By middle childhood, forming an identity is partly built around defining similarities and differences between siblings. When children ask themselves how they are similar to and different from their sibling with a disability, they do so with an awareness that they may have some advantages not shared by their sibling.

Carr-Gregg and Shale suggest that throughout adolescence children must complete four tasks in the process of developing their own unique identity. Adolescents begin the search for a secure and positive identity by asking questions such as: Who am I? They then seek to establish some emotional independence from their parents and other adults, sometimes by questioning their authority and knowledge. Adolescents then seek to establish a love relationship outside the family, and friendship and peer acceptance becomes of paramount importance. During middle and late adolescence, young adults start to consider career options and begin planning and setting career goals. <sup>6</sup>

Bank and Kahn note that the quest for a secure identity is achieved by asking: Who are you to me? Why should I be with you? What do we have in common? <sup>7</sup> Siblings of a child with a disability can find themselves in a state of conflict when they ask these questions.

For example, when schoolmates tease other children with disabilities or think it is dangerous to sit next to the child with a disability in case they catch it, what do siblings think of themselves? If they join in and tease the child with a disability to reassure themselves they are still part of the group, they may feel they are being untrue to the love and care they feel for their sibling with a disability. If they resent their sibling getting presents from relatives because they are sick, then they are not the good child mum and dad praise for helping out with the household chores. If mum and dad praise them for being so grown up, helpful and caring, then who owns the angry, jealous and resentful parts of themselves?

"Part of my struggle in dealing with Bonnie was a need for my own identity, apart from her. When we were toddlers, Mom used to dress us alike. During my grade school years I thought of Bonnie as a witch. I felt like everything I did, Bonnie had to do also. I could not get away from her. If I took piano lessons, she had to take piano lessons. When I was in Girl Scouts, she was in Girl Scouts (Mom started a troop for retarded girls). She wanted to be like me, and yet I wonder what kind of role model I was." <sup>8</sup>

During adolescence, a person's source of identity begins to shift, or dissolve, as they begin to question their accepted role in their family and their parents' values and attitudes. They may need more time and mental space to try out new roles in the search for their own identity. For example, if a family is not able to obtain enough respite, teenagers may find themselves having to choose between helping out with their brother or sister to assist their parents, and pursuits such as friendships and schoolwork. As they consider their future career, siblings may need help to give themselves permission to focus on their own needs. For some, the anxiety of choosing between these conflicting roles may become too much, resulting in a lowering of their expectations.

Questions asked by children regarding their sibling's disability, illness, behaviour or appearance need honest and simple answers. This is important to dispel fears of catching their sibling's illness or disability and will assist in the development of their unique identity. Another important way for siblings to develop a positive self-image is through developing skills in areas of life not related to their brother, sister or parents, and which are celebrated by their parents.



# Emotional Responses

## to having a sibling with a disability or chronic illness

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### Fear and Anxiety

#### 'Did I make this happen?'

Preschool children have a very narrow view of the world and tend to link events to themselves. This egocentric view means that at some time, young siblings tend to think they either caused their sibling's disability or fear they will catch it. Given that preschool children may not be able to articulate these fears, it is helpful if parents are able to explain the disability and reassure them. Young children also tend to think in very concrete ways, that is, they need to see something in order to understand it. Simple explanations that include one or two visible features of their sibling's disability and a statement that they did not cause it and they can't catch it would clarify their understanding of the situation. In order for the child to remember and integrate the information, these explanations should be repeated over time.

Given a young child's cognitive limitations and their egocentric view of the world, witnessing a sudden change in their sibling's health can result in a fear response. While preschool children can name their emotions, they may need help to understand them within a particular context. Young children rely on parents to allay their fears until they are able to help themselves. The degree to which a child responds with fear to their brother or sister's disability or illness is related to their age, their temperament and their life experiences. With the assistance of parents these fears can be negated or managed.

Young children are also prone to linking events in a causal way. For example, if a young child sees their brother or sister having a seizure they may think that they caused it or that it could happen to them. They may also think that by changing their own behaviour (if they think they are responsible), they can stop their sibling from becoming ill.

#### 'Will my friends think I'm disabled too?'

As a child enters school, they start to become aware of differences between people. They are exposed to different attitudes among their peers and they are learning how to be part of a group. School aged children are also capable of understanding more about their brother or sister's illness or disability. These two changes can create a need for different responses from parents. For this age group, parents need to be mindful of their child's ability to understand their sibling's disability and also their capacity to explain the disability to their peers. Discussing likely questions or comments may prepare the child by letting them find and use words they are comfortable with.

By the age of eight or nine, children can begin to understand other people's experiences. A child's impulse is to actively cope with a situation by wanting to do something to help their sibling but they will need assistance from their parents either through information or strategies.

**"I was certain everyone was looking at my brother with his obvious handicap and then wondering what was wrong with the rest of us." <sup>9</sup>**

In early adolescence children begin the process of forming their own identity. They begin asking themselves questions such as: Am I normal? Do my peers like me? Am I an OK person? <sup>10</sup> During this time, children become very conscious of what is considered normal. An intense desire for acceptance results in a fear of group rejection if they appear to be different. It is not uncommon for adolescent siblings to fear rejection once their peers become aware that their family is different.

**"He hits me every day. He just all of a sudden hauls off and hits me all of a sudden. I don't know why. My Mom says it's part of his hyperactivity. My Mom tells me not to worry about it, that it will get better. I don't see how. The other day he sat on me and it was hard to breathe. But I know that if I fight him back it will be worse. So I try to wait it out. I worry sometimes that he might kill me. I know he wouldn't mean to, but I think it could happen." <sup>11</sup>**

For some siblings, fear of their brother or sister can be based on a real threat to their own or their parents' safety. These siblings often fear for their parents' well-being and the subsequent loss of their security. If the child with the disability is aggressive or has unpredictable behaviours, then the need for support through either talking or active coping strategies, is very important.

## **'How can I be myself and be responsible in the future?'**

By adolescence, siblings are becoming aware of the full ramifications of their brother or sister's disability or illness. Questions regarding their sibling's future development and independence can lead to concerns over the likely impact on their own life and that of their parents.

At this time, adolescents are in the process of creating a pathway for their own future and their identity is still insecure. Depending on the severity and cause of the disability or illness, the adolescent will be confronted with parental expectations and perceived responsibilities as a family member and as a sibling. The likely response from the adolescent will be anxiety. This additional worry about the ongoing responsibility and care of their sibling, coupled with the normal concerns of most adolescents (education/career choices, their identity amongst their peers and forming intimate friendships) can amplify existing anxieties.

In order to dispel these fears and reduce anxiety, parents could discuss their future plans for themselves and the child with the disability as well as the expectations they have of the sibling. Adolescents need reassurance from their parents that it is OK to become an independent adult and that they will be supported as they move towards adulthood.

# Anger, Resentment and Justice

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**"Jane (7) reacts towards both her disabled brother Richard (5) and her mother by hitting her mother with her fists, expressing her hatred towards Richard. Alternatively, she will cry and chant prayers learnt at school reflecting her plight. She has defaced Richard's certificates received at school for various achievements. When Jane is staying with her grandmother, her extreme reactions disappear. She gets the attention she craves."** <sup>12</sup>

Like fear, anger is an emotion infants begins to display from the age of six months. It is an emotion that can overwhelm a child and one that is universally discouraged by parents.

While the preschooler may not express their anger towards their sibling with a disability or illness, they may experience anger and frustration over the lack of time and attention from their parents. The care-giving needs of the child with the disability may mean that the needs of the sibling are not met, often resulting in greater levels of frustration. Sibling anger is more likely to result indirectly from the loss of parental attention.

Unequal time and attention from parents can also lead to feelings of jealousy or resentment towards their brother or sister because they still equate love with attention. Unacknowledged jealousy can lead to feelings of anger towards their sibling, as it would in any sibling relationship. A common way of coping with anger may be to express it outwardly by becoming disobedient or playing up, which may include increased aggression towards their brother or sister. In families with more than two children who are relatively close in age, a child may also turn their angry feelings towards their other siblings.

**"My mother never let me feel that I always had to be happy about having a disabled sister, and in fact even encouraged anger about it, as long as I kept it in perspective."** <sup>13</sup>

In some families, the expression of anger about having a sibling with a disability is strongly prohibited and only positive comments about the child are acceptable. As a consequence, siblings may interpret their feelings of anger or resentment as evidence that they are bad. Siblings who feel angry towards their brother or sister with a disability can experience intense feelings of guilt and shame. Inhibiting expressions of anger or resentment can lead to the internalisation of negative feelings causing them to avoid the source of their anger (their sibling with the disability). Validating sibling experiences and feelings can assist siblings to acknowledge the source of their anger and resentment and can help them develop insight and find constructive ways of coping.

Many siblings try to protect their parents from their negative feelings. Some siblings feel that expressions of anger or frustration about their experiences would be unfair, given the difficulties that their parents face on a daily basis. Expressing anger may also risk the image they like to present to their parents, of being happy and self-sufficient. When the family is the main source of self-esteem and identity, the risk may be too great.

**"I feel bad for me because I wish I had a brother that I could really relate to. I wish I had a brother I wasn't somewhat embarrassed by. I wish I wasn't in the approach-avoidance slot of being my brother's keeper." <sup>14</sup>**

Throughout early childhood and adolescence, children have a heightened awareness of what is fair and just. Young siblings may experience anger and frustration over the unequal distribution of household chores, or attention from parents. Older siblings may feel a sense of anger about the unfairness of the world, or the injustice of not having a brother or sister who they can relate to in the same way as their peers.

**"At a time when you want to be (a) sulking in your room, (b) screaming you don't understand, and (c) looking for someone to snog, I had instead to play the part of the model adult-child." <sup>15</sup>**

During adolescence it becomes possible for siblings to articulate their feelings and express their thoughts and opinions. Part of their path to adulthood is to develop an independent voice. Giving adolescents the opportunity to express and explore their feelings will facilitate understanding between all family members and will reduce the risk of siblings withdrawing from their parents and their sibling with the disability.



# Jealousy

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"Alex has leukemia and he used to get big packages so I used to get very jealous. Wouldn't you? But over the year I got used to everybody feeling bad for him, and giving him so much attention. In some ways, I actually got something out of it, too. All I hope is that everything will be back to normal after this year." <sup>16</sup>

Before a child understands that their brother or sister has 'special' needs they are aware that their parents give more time and attention to their sibling. Attention from a primary care-giver is one of the main ways a preschooler develops a positive self-image. The risk is that the sibling will conclude that they are less special and less loved than the sibling with the disability.

## **'My sister gets all the best presents, I am always helping her but no-one even thanks me.'**

When other family members and friends focus on the child with the disability, a sibling's feeling of being less special may be magnified. If a sibling is going through a time of change, for example, starting at a new school or neighbourhood, they will need more time and support from their parents. If parents spend most of their time caring for the child with the disability or chronic illness, then strong feelings of jealousy can result.

A child's response to unequal time and attention will be influenced by the way their parents talk about their sibling with the illness or disability. In a perfect world, another parent is able to compensate for the child's significant loss of attention from the main carer. Otherwise, a grandparent, aunt, uncle, close family friend, or even an older sibling can help the child who thinks they are missing out.

## **'For them life is easy, why don't I feel like I belong?'**

In adolescence, a child strives to become independent, while maintaining a positive connection to their family, so jealousy in response to their sibling's disability is unlikely. They may instead feel jealous of their peers whose lives seem less complex. Siblings may be jealous of friends who appear to have greater freedom, who will be less likely to assume a caring role for their siblings or face complex dilemmas about their future. They may feel unable to relate to the concerns of their friends, which may seem trivial in comparison to their own.

It is common for siblings to have conflicting emotions regarding their family circumstances, for example, feelings of jealousy are often followed by guilt or shame. Siblings may feel jealous, desiring the perceived freedom of their peers, and then feel guilty about not being there for their family. With open communication and validation of their feelings, a sibling's reaction of jealously and resentment can subside over time.

# Embarrassment, Guilt and Shame

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"We were walking home from school, she and I, and the discussion was focused on my unusual little brother. Unusual, that is, to everyone else. To me, he was just my little brother. Since I only had one, he was unique, regardless of his other qualities. Anyhow, my friend asked me why my brother did not talk yet, as he was almost 5 years old. I thought for a moment and said, very seriously, "Well, he only speaks French and none of us can speak or understand French, so it presents a terrible problem." She nodded with vague comprehension of the "problem." I chuckled all the way home. We were in fourth grade." <sup>17</sup>

Feelings of embarrassment, guilt and shame partly depend on how a child has come to make sense of their own role and rights, and those of their brother or sister. Whether a family can appreciate different ways of living, and the degree to which the family gives value and meaning to the life of the child with the disability will influence how a sibling manages these feelings.

"I can remember being embarrassed about Cathy because she is really, I guess quite upsetting to see for the first time...I can remember in a bus terminal we had to spread a blanket on the floor so Cathy could crawl and get a bit of exercise. A crowd gathered and I hated the people so much. I was just terribly embarrassed and I wanted to hide Cathy and I wanted to protect her from these people who were glaring although she certainly didn't know what was going on." <sup>18</sup>

By middle childhood, siblings are very aware of other people's responses to their brother or sister with a disability. Differences between children at school are magnified and full of dreadful import. Young children will be experiencing feelings of embarrassment about their brother or sister's differences for the first time and will need help to understand their feelings. While children may know the right thing to do or say, the dilemma they face is meeting conflicting needs: the need to protect their sibling and the need for peer acceptance. Siblings can feel a sense of guilt or shame for not 'standing up' for their sibling or for not doing enough to help their sibling or their parents. For some siblings these feelings don't become apparent until adulthood.

"I remember on the bus, no one wanted Bonnie to sit beside them. One girl walked with a limp. Every day I would ask her if Bonnie or I could sit with her and she would always turn away and tell me the seat was saved, day after day, no one sat beside her, she sat alone and we stood. One day, I got fed up. I picked her books up off the seat and threw them at her. Then I sat on her and made enough room for Bonnie beside me. It was an uncomfortable ride home, but I was tired of standing and I wanted to show people that they would not "catch mental retardation" sitting beside Bonnie." <sup>19</sup>

Given that their identity is not yet secure, feelings of shame and guilt can be amplified for the young adolescent. Siblings discover that community attitudes towards disability or illness are often contradictory or confused. While some differences are celebrated within our culture, we tend to consider people with disabilities as 'lesser' which is evidenced by the use of insults such as 'retard'. Some siblings cope with the social stigma attached to disability by creating a layer of pride to protect themselves from negative attitudes.

By adolescence, feelings of guilt and shame are often felt when children are able to empathise with the experience of others. Guilt or shame often follows feelings of anger, embarrassment or jealousy. All children need attention, resources and special time with their parents and when a child starts to understand why their parents have limited time for them, feelings of guilt often result. These feelings can also emerge when siblings begin to understand that they have advantages that their sibling doesn't have. Having a girlfriend or boyfriend, friends to socialise with and prospects for a career can expose the stark contrast between their own life and that of their sibling. Siblings with a brother or sister with a chronic or degenerative illness may feel guilt about their own good health and opportunities in life.

**"I remember being so angry at her, and then feeling so guilty. She was defenceless. I lay awake at night praying that God would forgive me for having such thoughts about my sister. The range and intensity of emotions were too much for me to handle." <sup>20</sup>**

Children will actively seek ways of coping with negative feelings and experiences. While religion can bring about a sense of security and solace, parents need to be mindful of children praying for miracle cures or seeking forgiveness from God in order to deal with their feelings of resentment, jealousy and anger. Listening to children and helping them to understand they are not bad people for having angry thoughts, accepting them and supporting them will help to offset feelings of guilt and shame.

It is important for parents to reassure their children that their feelings are valid, to give them strategies to cope with the reactions of others and to manage their conflicting emotions. By understanding and coping with the difficulties of family life, many siblings develop compassion and become appreciative of their own opportunities, which will in turn become the building blocks for their future emotional and psychological well-being.



# Loss and Sadness

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**"I'm sad that Randy's handicapped, but I know there's nothing I can do about it. My parents think Randy's special because other little sisters and brothers are ordinary sisters or brothers. Randy will always be special to me." <sup>21</sup>**

A sibling's experience of loss or sadness is closely tied to their stage of development and will depend on a child's capacity to comprehend their loss and that of their parents. For example, the response of a sibling who has a brother or sister with a degenerative or life-threatening illness will be influenced by their ability to understand what caused the illness, its future implications and their understanding of what death is.

**"Mom, I have an apology to tell you. When Shannon was born and you were in the hospital with her, I used to pray that God would take her and let you come home, or that God would make her all better, so that you would come to be with me. I missed you so much." <sup>22</sup>**

In early childhood, older siblings can feel a sense of loss for the parents and childhood they had before the birth of their sibling with a disability. This may include the loss of a sense of calm and security that existed before the birth of their sibling, as well as the loss of time and attention from parents. Their parents may be experiencing ongoing crisis and stress relating to hospital visits, long stays in hospital etc. As the family routines change around them, they can lose a sense of predictability and safety. For example, they may experience frequent trips to hospital or be sent to stay with relatives. Continuous upheaval can lead to feelings of fear and anxiety.

Young children do not have the ability to verbalise their feelings; they express them through their behaviour. This can include attention seeking for comfort and reassurance, aggression, rapid changes in mood and sometimes regression to an earlier stage of development. These are a young child's way of coping with stress and strong emotions.

Once a child can empathise, they can become aware of their parents' and perhaps their sibling's suffering. When parents explain the nature of the disability or illness and encourage children to talk and describe their feelings, they tend to cope better with the losses in their life. In many cases, siblings will continue to worry about their brother or sister with the disability. Siblings may cope by continuing to ask questions and seek assurance from parents that they are OK, and that it is not their fault.

**"John and I do not talk with one another, I wished we could. My friends have brothers who tell them about the high school and the teachers and what to do and what not to do." <sup>23</sup>**

**"I wish that someone could know what it's like for me to be all alone. I have to go to pumpkin patch until dinnertime instead because mommy and daddy are in the hospital. Then the baby-sitter picks me up and we have dinner. The other kids don't understand, so I don't feel like playing with them." <sup>24</sup>**

In the teenage years, feelings of loss and grief about having a sibling with a disability can be confusing. Having grown up with their brother or sister, they have integrated their sibling's disability into their understanding of how the world is. Their grief stems from developing insight into what they and their brother or sister have lost in comparison to their peers.

These feelings of grief can be disturbing when siblings are unable to share their experiences with the people they usually feel close to (friends or parents). To suppress or ignore these feelings can influence how they relate to their brother or sister, in the present and future.

Parents need to be mindful of the need to assist in building positive relationships between siblings. When small achievements are celebrated, the sibling relationship will be linked to positive experiences. This can play an important role in offsetting a sibling's sense of loss and grief for the 'normal' sibling relationship.

In middle childhood, feelings can fluctuate rapidly, causing confusion. They can change from admiration for their brother or sister in one instance, to resentment due to their perceived loss in another. If a sibling experiences resentment and anger during periods of palliative care because of their own loss and stress, their feelings of guilt and shame can be linked to grief.

Given that siblings may face a lack of understanding from others, their sense of being different, alone and burdened can increase. In this state of heightened vulnerability they may cope by keeping their experiences and feelings to themselves.

Feelings of grief about the death of a sibling is related to their stage of development and their understanding of death. If a sibling dies, a young child will only realise this over time, as they cannot immediately grasp the finality of death. They will continue to express how they feel through their behaviour.



**"There may be vague bodily complaints, confused thoughts about blame, regression, or anxieties about being abandoned. Many bereaved children turn to play or other familiar routines to regain a sense of security in their lives." <sup>25</sup>**

By late childhood, they can begin to understand more about their brother or sister's medical condition and may fear for them. They may blame others and worry about the effects of the illness on their parents or sibling. Until they can grasp the cause/s of the illness, they may fear for their own health. They may fear that if their sibling is ill or has died from an illness that it may happen to them, or to their parents. Talking with adults will be important in helping them deal with their fears and any misunderstandings they may have about their brother or sister's condition and consequent death.

For example, one grief counsellor helps children in their grieving process to understand the permanence of death this way:

**"I take them through the fact that when somebody dies their heart stops beating. I make them put their hand against their chest so they can feel their heart is beating and that their skin is warm and that's good because the blood goes around the body. Because otherwise they do worry..." <sup>26</sup>**

When a child who has required complex care over a long period of time dies, the family, which has been supported by a range of individuals and services, can rapidly lose these people from their lives. A sibling may have developed close and supportive relationships with certain service providers and have to adjust to the loss of these people's support. <sup>27</sup>

**"Rebecca has taught me so many things. I've learned how to be patient, understanding and caring. How to love fully. I've learned to take time for the little things in life, like looking at the trees and watching the leaves blow (one of "Reba's" favourite things to do). To my amazement, I love the life I have because of her...I would never trade it in for anything else! I learned that when in life we're faced with challenges, we should deal with them the best way we can, we should take time out for ourselves, and we should never give up!" <sup>28</sup>**

For adolescents, the process of bereavement carries great challenges due to their developmental tasks of creating a stable sense of identity, becoming autonomous, and deciding on a future career path. The grief they experience can lead to feelings of isolation (as peers may respond to them with fear) and a loss of confidence in themselves. If an adolescent already has a low self-concept, then their process of grieving can be more difficult and further lower their self-image. They can lose trust in the predictability and fairness of life causing them greater anxiety and fear than their peers. With support throughout, they can draw meaning and strength from their experience.

# Loneliness and Isolation

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**"I was four when the severity of his [my brother's] condition was unfolding. At this crucial juncture, when I needed my parents for my own growth and development, they were drowning, emotionally, while the severity of Mark's condition was becoming apparent." <sup>29</sup>**

While an infant may not feel lonely, they can experience a sense of anxiety. When an infant's security of attachment is disrupted, they can become more vulnerable to negative emotions. Later on, if parents become unavailable either physically or emotionally, siblings may experience feelings of abandonment. Parents often inhibit the expression of any negative feelings and this can result in a sense of isolation and feelings of shame. In the long term this may affect how they relate to other family members, their parents and their friends.

As children grow older, they develop the capacity to understand other people's experiences, that is, 'to stand in someone else's shoes'. When they look at their family circumstances and the additional care required of their sibling, they begin to understand why their parents need to spend more time with their sibling who isn't as 'healthy' or 'able' as themselves. An awareness of how their parents have struggled, coupled with the desire to adopt a role of competence and responsibility, can result in siblings not wanting to share their troubles with their parents. Yet they can still experience anxiety, loss, and strong and confusing emotions.

**"The best thing I ever did was to go to the siblings support group. It was so cool, and best of all I learned that I wasn't crazy...that other kids felt the same ways I did. I made a friend there, so now when I feel lonely or sad, I just call him up, or he calls me." <sup>30</sup>**

Just as parents benefit greatly from sharing their experiences with other parents in a similar situation, so too do siblings. However, siblings often fear that they will be judged harshly for expressing the negative emotions or thoughts they may have towards their brother or sister or their parents.

**"It was eerie actually. The doctor looked right through me as if I was a plant or something. He just talked to my mom. There I was, scared out of my wits, my sister asleep in a bed with a high fever, and all those tubes and equipment...I felt angry and confused and pretty lonely too. She's my best friend." <sup>31</sup>**

When siblings lack the opportunity to talk with friends or peers and feel unable to voice their feelings or problems to family members, they may feel alienated from those they are closest to. These feelings of loneliness and invisibility can be compounded when service providers do not acknowledge their involvement.

# Emotional Intelligence

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"Whenever Mommy and Daddy argue, we go downstairs and play real quiet. Then she can't go bother them and get 'em more mad." <sup>32</sup>

Up to six or seven years of age, a child's response to the world is self-centred. For example, Lobato notes that before this age, children evaluate their brother or sister in terms of how they gratify them, or not. By age seven or eight, children begin to describe their sibling's positive traits. They are aware of, and express, their enjoyment of their sibling's company. They are also aware of, and can try to influence, how other family members are feeling. For example, if a child senses a parent's disappointment, grief or loss, they may try to make up for it by being really helpful, or doing well in sports or school work. What they do will depend on what is valued by the family and the encouragement they receive from family members.

Given that it may not be possible for parents to give equal attention to their children, siblings gain praise and validation by being helpful and compliant. Siblings may also compensate for their family difficulties by putting aside their own needs whenever they sense it will be difficult for their parents to meet them. By middle childhood, siblings may be contributing significantly to the sibling relationship by helping their parents or being a good brother or sister. When siblings put aside their own needs, feelings of loss may occur.

From early to late adolescence, compensation for their parents' hardships, disappointments or losses may continue to influence sibling motivations and actions. Trying to compensate may not necessarily pose a risk to sibling well-being, as it may drive them to develop skills and abilities that enrich their life and those around them. However, if the need to compensate for their family's hardships is constant, it may pose a risk to a sibling's self-esteem and identity. For example, if a sibling fails at school they may feel they are letting their parents down, or worse, feel guilty for not using their abilities to the fullest.



# Strategies to Think About

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- Give honest and simple explanations regarding the disability or illness. It is important to use language that is age appropriate. It is likely that these explanations will need to be repeated over time.
- Reassure young siblings that they did not cause their sibling's disability or illness, nor will they catch it.
- Explain the reasons for differential treatment and for the different rules and expectations that may be applied to the child with a disability.
- Encourage children and adolescents to participate in interests outside of the family. Praise them for their efforts.
- Acknowledge siblings for their efforts in being a 'good' brother or sister. This is an important way of supporting the development of their identity and self-esteem.
- Discuss your future plans for the care of the child with the disability to help to allay any concerns siblings may have regarding their role in their sibling's future care needs.
- Provide siblings with an opportunity to explore and express their feelings, both positive and negative.
- Reassure siblings that their needs, experiences, feelings and concerns are valid.
- Give siblings simple strategies to help them cope with difficult situations, eg. teasing in the playground.

# In Summary

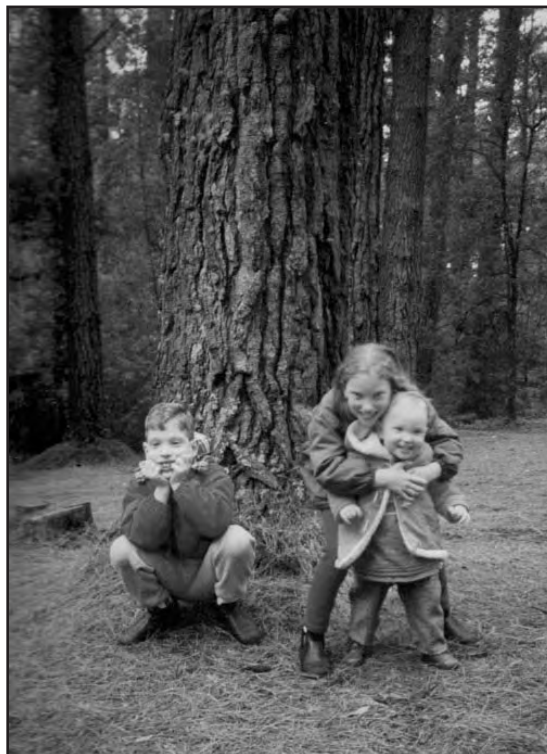
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Many of the emotions and experiences discussed in this section are not unique to children who grow up with a brother or sister with a disability or illness. Every child's experience is unique, as are their life histories, which shape their responses to particular situations.

In this section we have sought to describe some common emotional responses to growing up with a brother or sister with a disability or chronic illness. Drawing on research, we have endeavoured to understand sibling experiences within the context of their stage of development.

By considering sibling responses in the context of their stage of development, we can see how very 'normal' these responses are. We hope to draw attention to the richness of the sibling relationship and their responses to what can be difficult experiences. By doing so we can see the ways in which young siblings make sense of their challenges, develop strengths in themselves and in their relationships.

Having focused closely on the inner world of young siblings, we now look outwards to their family and social environments to consider what might assist siblings to cope well with some of the challenges that might arise when they grow up with a brother or sister with a disability.





## **Section 2**

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### **Family and Social Influences on Sibling Adjustment**

# Family and Social Influences

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"Most siblings will be able to say there were some good and not so good aspects of their experience." <sup>33</sup>

Lobato conducted extensive research on factors that influence sibling adjustment to having a brother or sister with a disability or chronic illness. Lobato concluded that factors such as age, gender, birth order and the type and severity of disability each play a role in how siblings adjust. Other family characteristics such as the way people feel about one another and cope with stress, also play a major role in sibling adjustment. This section considers how a sibling's family and social environment affects their ability to cope. The factors we will consider include:

## The Family Environment

### Parents

- Parent Attitudes to Disability
- Parent Well-being and the Couple Relationship

### Siblings

- Gender and Temperament
- The Sibling Relationship
- Type and Severity of Disability or Chronic Illness

### Family Structure

- Single Parent Families
- Family Size
- Birth Order and Age-spacing

### Family Functioning

- Care-giving and Household Tasks
- Communication

## The Social Environment

- Cultural Attitudes to the Sibling Relationship
- Cultural and Community Attitudes to Disability
- Availability of Resources

# The Family Environment

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## The Family Relationship

How a child responds to growing up with a brother or sister with a disability will be mediated by factors such as age, position in the family and the way family members interact with one another. When a child is born with a disability or illness, each family member will have the need for greater physical and emotional care from each another. The amount of additional care or attention required will vary, and it will also influence the way family members relate to one another. Research shows that positive sibling adjustment is more likely to occur in families where there is open communication and warm and cohesive relationships. For siblings of children with a disability, such family environments provide the child with the necessary skills to deal with their conflicting emotional responses.

## Parents

### Parent Attitudes to Disability

**"Our children's views sometimes threaten the beliefs that enable us to cope with our situation. Even after we become more comfortable with ourselves, our children's unhappiness touches us deeply." <sup>34</sup>**

A parent's attitude to their child's disability influences sibling adjustment in a number of ways. These attitudes to disability derive from different aspects of their life: personal history, the circumstances surrounding the birth and diagnosis of their child and the capacity of their surrounding community to support the family. Parent attitudes to disability may also change over time as they adjust to their changed family circumstances. In this report, parent attitudes to disability and their influence on sibling adjustment is concerned with long term attitudes held by parents which stretch beyond periods of loss and grief.

Children tend to adopt the attitudes of their parents. Featherstone argues that siblings learn to give value to their experience of having a brother or sister with a disability by watching their parents. <sup>35</sup> A study by Grossman found that the strongest influence on a sibling's acceptance of a brother or sister with a disability is how the parents, especially the mother, understand and respond to the child with a disability. <sup>36</sup>

**"When brothers and sisters describe their own experiences, they consistently emphasise the importance of their parents' reactions, level of acceptance and adjustment." <sup>37</sup>**

Lobato believes that the parents' response and process of adjustment has a significant influence on a sibling's perception of their situation and how they cope.<sup>38</sup> Lobato linked parent attitudes to how siblings cope in the following ways:

- If parents express (on average) more negative emotions about their situation and express resentment towards the child with a disability, then each child in the family will share these feelings. Alternatively, where both parents express positive feelings, each child shares these good experiences.
- When parents present the perception that the family's problems have resulted from the child's disability or illness, siblings are likely to adopt the same belief.

Research suggests that parent attitudes to disability can set the tone for family life. Positive parents convey hope and resilience, whereas parental perceptions of anger or resentment towards the child with the disability are likely to be adopted by siblings. It is also important to acknowledge that siblings need to express both their positive and negative feelings regarding their sibling relationship.

## Parent Well-being and the Couple Relationship

**"It appears clear that a mother's own adjustment is critical to siblings. Mothers who report symptoms of depression and physical fatigue are the ones whose children also exhibit more problems with self-concept and behaviour at home and at school. In fact a mother's mental and physical health is probably more important in determining sibling adjustment than the presence or absence of the child with the handicap or chronic illness in the home."**<sup>39</sup>

According to Lobato's research, the mother's physical and psychological health is the most important predictor of sibling adjustment regardless of the existence of disability in the family.<sup>40</sup> As with parental attitudes, a parent's sense of well-being is likely to change throughout their experience of loss and grief. If the diagnosis of a disability or chronic illness in a child triggers depression for the parent, then the parenting of all their children will be affected. Support for parents at the time of their child's diagnosis is likely to have a positive effect on coping for the family as a whole. Lobato found a strong link between a parent's sense of well-being and the degree to which they felt supported in their relationships.

**"When parents perceive little support from their partner and/or others, they are more likely to show significant signs of depression and fatigue that can translate into problems for their children."**<sup>41</sup>

**"Siblings do best psychologically when their parents communicate their expectations and feelings openly, talk about the illness or disability honestly, do not overburden them with child care and household responsibility, and manage to maintain pleasant and supportive marital relationships. While these family styles of coping do not make the sadness of a child's illness or disability disappear, they do seem to enable brothers and sisters to develop some of life's most admirable characteristics."**<sup>42</sup>

Parent well-being and satisfaction in the couple relationship are linked to sibling adjustment in the following ways:

- Families with parents who feel satisfied and supported in their relationship with their partner and who report low levels of conflict in their marriage, are more likely to have children who are helpful towards one another and who exhibit fewer behavioural problems. <sup>43</sup>
- A good relationship between parents, along with low family stress and a supportive and expressive family environment, helps children manage their problems. <sup>44</sup>
- Conversely, difficulties in the parent relationship, family stress, and a lack of family cohesion and expressiveness has been linked to an increase in sibling issues.
- Self-esteem in siblings is related to the degree of happiness in their parents' marriage. <sup>45</sup>

A positive relationship between parents enhances sibling coping and adjustment in the following ways:

- Siblings experience more consistent parenting strategies. <sup>46</sup>
- Parents receive more support from each other and so are less at risk of depression caused by feelings of stress and isolation.
- Less conflict makes for a more open and positive tone of family life.

Research suggests that a parent's physical and mental well-being, plays a critical role in how siblings adjust over time to growing up with a brother or sister with a disability or illness. This is true for all children. Siblings will be more likely to develop resilience and self-esteem if they receive support from their parents.



# Siblings

## Gender and Temperament

Both the gender and temperament of a child can influence how they adjust to growing up with a brother or sister with a disability or chronic illness. These factors influence not only the adjustment of the individual sibling but also the development of the sibling relationship.

**"When temperamentally difficult children are exposed to stressful life events...their problems are magnified." <sup>47</sup>**

Great change and an ongoing process of adjustment generally accompany the birth of a child with a disability or chronic illness. As a result, there can be ongoing stresses to which all family members are exposed. <sup>48</sup> Young children can be vulnerable because they lack the ability to mentally comprehend the disability or illness. Temperamentally difficult infants display a negative disposition and a tendency to withdraw from new experiences or people. Siblings with difficult temperaments may need more support to cope with and manage the stresses associated with this change.

Strohm cautions parents and teachers to be concerned for the 'easy' child as well as the one acting up. Strohm suggests that "It is also important to understand that a quiet, so called 'easy' child is just as much at risk of distress...Parents and teachers often overlook these children because they don't disrupt daily activities". <sup>49</sup>

Lobato found that gender is related to sibling adjustment in the following ways:

- Siblings tend to feel greater embarrassment due to their sibling's behaviour when they are of the same gender. <sup>50</sup>
- Being close in age and of the same gender can make the process of establishing a separate identity harder for some siblings.



## The Sibling Relationship

"I feel Ben and I have an indefinable understanding – we can read each other in a way mum and dad can't. I guess this means I'm often sceptical of other people's opinions of Ben. I find it funny when people say he cannot grasp the concept of humour, yet I often find him giggling at John Cleese's or Mrs Bucket's crazy antics. They say he cannot look after himself, yet he's capable of opening the pantry and stuffing himself with chip packets they say he doesn't have the fine motor skills to open. They say he doesn't understand sarcasm or manipulation – but boy-oh-boy! The number of times he's faked sickies vitiates any doubt I may have had there!" <sup>51</sup>

The sibling relationship can contribute negatively or positively to a child's well-being. For most children, the birth of a sibling is both an interesting and stressful event for the firstborn. A study by Dunn noted that the development of sibling relationships could vary a great deal. Some siblings developed a mostly co-operative and loving relationship, while others expressed hostility and aggression towards each other. <sup>52</sup>

Social interaction between siblings provides learning opportunities, modelling behaviours and social skills, and is beneficial for each child's socialisation. <sup>53</sup> Despite their differing levels of ability, siblings of children with a disability will actively seek creative ways to interact with their brother or sister, whatever the impairment or illness. For siblings, these interactions have been linked to the development of valuable skills. <sup>54</sup> It may also boost self-esteem when siblings feel that they can be successful as a brother or sister, and gain recognition from their parents and sibling on this basis.

A child's ability to cope with stressful experiences can influence how they perceive their relationship with their brother or sister. We have already noted that coping skills and temperament can influence how the sibling relationship develops. There are a number of other factors that affect sibling coping:

- Fear for a parent or sibling.
- Confusion and worry due to a parent's continued absence from home.
- Loss of an anticipated well sibling (if a disability or illness is diagnosed from birth).
- The interaction between the older sibling and his/her parents throughout the process of adjustment to the child's diagnosis.

"Some changes I'd like my parents to make for me are to STOP comparing me to him...I feel ignored a lot. And I want my parents to stop pitying Brian! If he does something bad, he gets yelled at. Then if he starts to cry, my parents rush to him and say, "Aw, what's the matter Brian?" But if I get yelled at and start to cry they don't even care. They just say, "Stop it, Jaci. There's no reason you should be acting like a 2 year old." It's always the little things that get me mad." <sup>55</sup>

The parenting of individual children also has an influence on the sibling relationship. While all parents treat their children differently, research has shown that for families with a child with a disability, siblings are treated differently to a greater extent; however, not all siblings respond unhappily to receiving different treatment relative to their sibling with a disability or illness. <sup>56</sup>

Aspects of parenting which have been found to increase conflict between siblings include:

- When parents show favouritism towards one child, regardless of disability. <sup>57</sup>  
If favouritism is combined with the (at times necessary) differential treatment of each child, siblings are more prone to experience conflict in their sibling relationship. This can have a negative impact on the development of both siblings.
- If a child believes his or her sibling receives poorer treatment compared to them, they may feel guilty. <sup>58</sup> One study of sibling views on relative treatment from parents contained a negative sibling response towards their parents because of the sibling's perception that the parents did not do enough to assist their sibling with the disability. <sup>59</sup>

Aspects of parenting found to contribute to a positive relationship between siblings include:

- Parents who give consistent explanations at their child's level of understanding increase a sibling's ability to cope.
- Sibling relationships are also likely to benefit from early intervention services where parents learn to help their children to play together co-operatively. Powell and Gallagher noted a number of methods that parents can employ to foster play and positive social interactions between siblings with and without a disability. <sup>60</sup>

## Type and Severity of Disability or Chronic Illness

The type and severity of illness or disability may influence sibling adjustment, for example:

- The type of disability can influence the level of support the family receives from the health and disability sectors. For example, it may be more difficult for a family to obtain services for a child with behavioural problems.
- The characteristics of the disability can pose specific challenges to family members. 'Having a sibling with an autistic disorder, ...may produce different demands than having a sibling with another chronic medical condition.' <sup>61</sup>

Lobato found no direct relationship between the type and severity of disability and the psychological development of siblings. Lobato believes it is one factor that can have an impact when combined with other factors, such as a family's income. <sup>62</sup> For example, extra care-giving demands could be met by obtaining outside assistance if a family has a higher income and the capacity to obtain services, rather than having to rely on siblings to meet these needs.

The day-to-day experience of siblings can differ depending on the type and severity of their sibling's disability. It is important that parents and service providers gauge how well siblings understand the disability or illness of their brother or sister and how it impacts on them.



# Family Structure

## Single Parent Families

Growing up in a single parent household is not uncommon in Australia. At the time of writing this report we found no research that considered single parent families or remarried and blended families as factors in sibling adjustment.

## Family Size

Children whose only brother or sister has a disability or chronic illness are vulnerable to feeling like an only child but lacking the benefit of their parents' attention. Lobato found that in families with at least two healthy, able siblings in addition to the child with the disability or illness, siblings were more socially competent and displayed fewer behavioural problems.<sup>63</sup>

Having more than one sibling in a family may affect coping in various ways:

- Children with more than one sibling have the potential to provide each other with support.
- Where there is more than one sibling there is often less pressure to become the 'super achiever' in order to please parents.
- When there are other siblings, children are able to share their thoughts and feelings with someone they are comfortable with and who understands.

While large families can share the care-giving and household tasks between more family members, they can also be burdensome for parents and siblings when there are few resources available. At least one study showed that a large family could be negatively related to sibling adjustment, as lack of resources could lead to 'chronic family tension'.<sup>64</sup>

Extended family networks of grandparents, aunts, uncles, nieces and nephews can provide a supportive and sociable environment for parents and siblings. These family networks can assist families in a variety of ways; giving them emotional and material support, providing respite for siblings, preventing family isolation and assisting with the care-giving needs of the child with the disability or illness.

## Birth Order and Age-Spacing

Lobato argues that age-spacing and birth order are important factors that influence sibling adjustment because, "The closer in age two children are, the more similar they are likely to be in their interests, abilities, desires and needs. Thus, there would be more occasions for identification, conflict, rivalry and resentment."<sup>65</sup>

Siblings who are younger or closer in age could be more prone to difficulties in coping because of identity concerns. For instance, "The sibling must learn to adjust his or her own identity in relation to a sibling who has a disability and, therefore, does not perform as a person that same age would typically perform".<sup>66</sup>

Birth order and age-spacing may create additional challenges to the sibling relationship:

- Adjustment problems may occur for siblings of older children with a disability.<sup>67</sup> If the child has a profound intellectual disability, their care needs may increase over time. So too might their ability to physically harm themselves or others.
- Siblings who are close in age may have a negative impact on parenting, given the likelihood for increased stress. This may also impact on the couple relationship.
- While some research suggests there are fewer adjustment problems for siblings when there is a large age difference, others suggest the opposite.<sup>68</sup> Some researchers argue that the sibling who has experienced some years of stability before the diagnosis will have a different experience to one that is born after a child with a disability, given that the family is likely to have adjusted to their changed circumstances.
- In the case of older siblings, the disruption to family life when a child is born with a disability or chronic illness can pose a threat to their sense of security. It is important for older siblings to spend some time with their parents in order to reassure them that the family unit is secure and supportive.
- Siblings who have formed a relationship with their brother or sister before the diagnosis of an illness or a disability, or if the onset is acute, may experience the diagnosis as a traumatic event.
- Regardless of birth order, "Less adaptively competent children seem to place greater demands for care-giving on siblings".<sup>69</sup>
- Younger siblings may have to perform care-giving tasks well before they are developmentally able.<sup>70</sup>

While it appears that birth order and age-spacing do not have a direct impact on sibling adjustment, they may be influential when other factors are taken into account (eg. parent well-being, the number of children and the extent of family resources) especially if they predispose the family to experiencing greater stress.

# Family Functioning

## Care giving/Household Tasks

"My friends didn't go home to perhaps give their sister a bath, or feed her dinner, but I'd grown up with her there and it really didn't bother me. Having said that, there have been times when I have felt that it was very unfair that I had to do these things (when it seemed) that nobody else did. The question, why should I? would flash through my mind, quickly followed by the answer: because Mum is trying to make dinner for Jenny and dinner for the rest of us, Jenny is crawling through the kitchen getting in the way, Kim is out at a music lesson, Dad is still at work, and I'm here. Unfortunately for me, I have a hyperactive conscience when it comes to these things. Most young people with siblings who have a disability probably do." <sup>71</sup>

Performing more care-giving tasks than their same age peers has been linked to negative outcomes in some siblings, including increased anxiety, irritation, conflict with their sibling with the disability or illness and varying degrees of depression. <sup>72</sup> However, taking on a care-giving role has also been linked to some positive aspects in siblings such as a sense of self-competence and of being a valued family member. <sup>73</sup>

The extent to which siblings take on care-giving responsibilities will depend on family resources such as income, accessibility to services, the severity of disability or illness, and the sibling's age and gender.

- Family income and family size can mean some siblings are required to accept a higher level of responsibility, including care-giving and household tasks. <sup>74</sup>
- Research has shown that the eldest female siblings have higher responsibility for tasks such as personal assistance, adaptive tasks, meal preparation and baby-sitting.
- Gender has been shown to influence the allocation of tasks, with male siblings being given greater responsibility for household tasks.
- The impact that care-giving responsibilities have on siblings becomes more complex when we consider children who feel compelled to accept these responsibilities despite lacking the physical and psychological maturity required.
- The manner in which young siblings take on adult levels of responsibility often occurs gradually, making it difficult for family members to identify when it has become a problem.

Accepting additional care-giving responsibilities may occur as a normal consequence of family members adjusting to the challenges of having a child with a disability or illness. To assist siblings maintain a balance between meeting their own needs while contributing to their sibling's and their parents' well-being, parents need to:

- Set boundaries on the degree of responsibility their other children are taking for their brother or sister with a disability.
- Let siblings know that their individual needs are important.

Care-giving and domestic responsibilities can be a source of positive self-esteem for siblings when their efforts are acknowledged and valued by family members; however, it is important that these responsibilities do not restrict siblings from activities outside the home or place them in situations that exceed their abilities.

In trying to reconcile the conflicting evidence about the positive and negative influences of care-giving responsibilities on siblings, Seligman suggests that, "It is possible that shared family care-taking and responsibility, along with expression of affection to all children in the family, promote a healthy, loving environment".<sup>75</sup>

## Communication

**"I felt increasingly lonely as I progressed through school, but I felt Mum was always there. I was always relieved when I came home to find her moving quietly but doggedly about the house, or watering the ferns or polishing the brass front tap. At one particularly lonely adolescent time, she said, 'When you were little I could always comfort you, but now I don't know how'. Her authenticity is still an abiding presence in my life."**<sup>76</sup>

Research has shown that open communication between family members is critical for each person's well-being.<sup>77</sup> In one study, siblings of boys with autism who did not have someone to talk to about their brother were more susceptible to depression. The author concluded that having open communication in the family and someone to talk to about the child with the disability was an important indicator of sibling well-being.<sup>78</sup>

Featherstone argues that in families of children with a disability or illness, communication can become stifled for a number of reasons, including a parent's sensitivities and responsibilities to each of their children.<sup>79</sup> When siblings sense that the subject of their brother or sister's disability or illness is off limits, they are less likely to express their feelings and concerns, which can lead to feelings of resentment and isolation. Seligman suggests that parents begin communicating to their children about their sibling's disability or illness early on, using language they can understand and which conveys the message that they did not cause it.<sup>80</sup>

Lobato states that, "Good communication and closeness in the family appear to provide the critical buffer between siblings and the added stresses of having a brother or sister with a handicap or chronic illness. This suggests that families who talk about and try to solve their problems together will create a better atmosphere for all of their children".<sup>81</sup>

Open family communication seems to be the underpinning of positive sibling adjustment. Positive sibling adjustment is more likely to occur when:

- Siblings are encouraged to voice their feelings and needs.
- Siblings are given accurate information at their level of understanding throughout their childhood and adolescence.
- Siblings have a good understanding of their brother or sister's disability, which means they are less likely to harbour feelings of fear, anxiety or guilt.
- Parents actively encourage open communication within the family, particularly around a family member's disability or illness.



# The Social Environment

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While the family environment has the most significant influence on sibling adjustment, it is also influenced by external factors such as culture and the availability of social supports and resources.

## Cultural and Community Attitudes to the Sibling Relationship

"Noah's condition dictated what we ate and when we slept and to a great degree how we lived. We never had fancy furniture because he chewed the couch cushions and spat on the carpets. He would pull apart anything more complicated than a pencil. I was ashamed of our home and family. Already marked as different by virtue of being Asian American in a predominantly white community, I came to see Noah as an additional stigmatizing mark."<sup>82</sup>

A family's cultural background can influence sibling adjustment via cultural attitudes to disability and expectations placed on the sibling relationship.

At the time of writing this report, there was no Australian research on the role of culture in sibling adaptation to growing up with a brother or sister with a disability or chronic illness.

An American study by Weisner found that culture was an important factor in understanding sibling experiences. Weisner compared the different cultural attitudes of parents to sibling roles and sibling experiences of growing up with a brother or sister with a disability. Weisner found that in western cultures, parents' expectations emphasised equal treatment for their children and focused on fostering independence, whereas in other cultures parents focused on fostering interdependence between the siblings.<sup>83</sup>

In this study, parent expectations were found to influence how they coped with making adjustments for each of their children. In comparing the two groups, researchers found that parents in Euro-American cultures experienced more conflict in parenting children with and without a disability or illness. This was because of their desire to show fairness to each child and because expectations of independence become problematic when one sibling is dependent on other family members.<sup>84</sup>

While these findings may not be transferable to the Australian context, this study highlights how culture can shape sibling experiences via the culturally based expectations of their parents.

## Cultural and Community Attitudes to Disability

Cultural attitudes toward people with disabilities are hard to measure given the degree of cultural diversity in our community. In Australia, we live in a culture that admires perfection, high achievement, independence and individualism. Given that people with disabilities often fall outside those valued attributes, it is not surprising that people with disabilities and their families often feel a sense of alienation from the norm or mainstream. At an institutional level, negative attitudes regarding the inclusion of children or young adults into mainstream life can be a source of enormous stress, frustration and anger for families. Families from culturally and linguistically diverse communities face additional barriers that hinder their access to mainstream life and can further isolate them from the community.

For the sibling of a child with a disability, the process of creating a unique identity involves establishing their role as brother or sister in the face of either positive or negative attitudes towards disability. If the attitudes are negative, then they share their sibling's stigma, if the attitudes are positive, then the sibling is identified in a way that recognises their influence.

Young siblings are aware of community attitudes towards their brother or sister and respond in different ways. In order to help siblings cope with negative attitudes from peers or adults, parents need to foster an environment in which siblings are encouraged to express their feelings and concerns.

## Availability of Resources

**"It appears that brothers and sisters of disabled siblings often feel insecure and it is not uncommon for them to be bullied. Their situation at home can be very difficult as a result of their having a disabled sibling. It is not surprising, therefore, that the transitions they are required to make can have a marked negative effect on their state of mind."** <sup>85</sup>

Research has found that the family environment has a significant influence on sibling adjustment, which includes the level of communication, parent well-being, and the availability of family resources.

Changes in social policy towards de-institutionalisation have resulted in a change of service provision which now focuses on supporting families caring for their child or adult with a disability at home. This process of de-institutionalisation has coincided with advances in medical technology which has resulted in the survival of many children with complex medical needs who are now being cared for in the family home. The availability of social supports such as the 'Disability Service System' is vital to families caring for a child with a disability or chronic illness. Unfortunately, governments have been slow to provide adequate services for families and many users of government services believe that the 'Disability Service System' in Australia has become crisis driven. <sup>86</sup>

Some communities have greater difficulty accessing services. A parliamentary standing committee found that people from culturally and linguistically diverse (CALD) communities, indigenous Australians and families living outside metropolitan areas are at a greater disadvantage in obtaining adequate services from the 'Disability Service System'.<sup>87</sup> Families living in regional areas face the added problem of living a significant distance from services and supports, which may result in both a lack of support and an increased sense of isolation.

While having access to basic services, such as respite care, allows siblings time with their parents or time to pursue other interests, such services are scarce and inadequate. Other barriers such as negative attitudes in the community and limited skills of service providers are harder to detect.

A sibling's wider social environment may support or hinder their ability to cope with any changes or stress in their life. When asked what schools needed to know about young carers, one young carer replied, "That if you're late on a morning it might not be your fault because a member of the family is disabled". Another said, "They need to know that when someone says something about our families it hurts our feelings."<sup>88</sup> The school community can provide support for siblings, but this often depends on good communication between parents and teachers and an awareness among staff of the effect that disability might have on a sibling's day-to-day life.

Research suggests that siblings should be encouraged to develop their individual interests and to balance strong feelings of identification with their sibling for the purposes of recreation and socialisation.<sup>89</sup> Service providers can support siblings better by providing opportunities for families to take up services currently on offer. They can also help create new services to meet the need for sibling programs in some regions of Australia.

The current ethos of service provision espouses family-centred practice, yet there are very few supports available for siblings. While there are some sibling programs across the state of Victoria, they are generally driven by particular interest groups and are not the result of a specific policy agenda to address the needs of siblings. The role of siblings forms an integral part of the life of a child with a disability, and deserves to be considered when policy-makers decide upon priority services.



# The Effect of Family and Community

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- Siblings tend to adopt the attitudes of their parents. Positive attitudes convey hope and resilience.
- A good relationship between both parents and a cohesive family environment has a positive effect on a sibling's ability to cope.
- Siblings of the same gender are likely to experience heightened feelings of embarrassment and may encounter more difficulties in forming a separate identity.
- Families in which siblings have more than one brother or sister have the potential to provide each other with support.
- Birth order and age can influence sibling adjustment when considered in conjunction with factors such as availability of resources and family size.
- Extended family networks can provide a range of supports; emotional, financial, social and material support which assist families in coping.
- Siblings often have responsibilities not shared by their peers. This can reduce their ability to participate in social, recreational or learning activities. Setting boundaries around the tasks and responsibilities that siblings take on will improve their opportunities to participate in activities outside the family home.
- Sibling programs can help siblings to learn more about their brother or sister's disability or illness and can be a source of support and understanding. While many siblings benefit from attending a sibling program, some do not have the opportunity to attend and others prefer different methods of support.
- Inclusive communities reduce the likelihood of siblings feeling isolated within their community and alienated from their peers.

# In Summary

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**“Resilience does not come from rare and special qualities, but from the everyday magic of ordinary and normative human resources in the minds, brains, and bodies of children, in their families and relationships, and in their communities. This has profound implications for promoting competence and human capital in individuals and society”.<sup>90</sup>**

Factors within a child's family and social environment have an effect on sibling experiences and coping. Research shows that aspects of the family environment (eg. parent well-being, their attitudes towards the disability and the extent of family cohesion) all impact on sibling coping. Family characteristics (eg. birth order and age spacing, the availability of resources and cultural and community attitudes) interact in complex ways and may further influence sibling experiences and coping. Recognition of the possible effects these factors may have on sibling experiences and coping can assist parents, professionals and others in a sibling's life to consider ways of supporting their needs.



# Conclusion

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Research has shown that in general, siblings of a brother or sister with a disability or chronic illness are not more likely to experience psychological difficulties than the rest of the population. It is also clear that when family members feel supported and are supportive of one another, siblings develop qualities that enrich their life.

The experience of living with a brother or sister with a disability is unique and is not widely understood by others in the community. This lack of understanding can pose particular difficulties for siblings. While siblings may have concerns to voice and insights to share, they do not always have the opportunity to do so.

We hope that this report inspires the reader to think of ways to provide siblings with opportunities to discuss their experiences. We hope too, that parents and professionals can use this report to reflect on ways they can better support siblings within the family context.



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## Other Resources

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### **[www.acd.org.au](http://www.acd.org.au)**

See the Association for Children with a Disability's site for the Sibling Program Directory for Victoria and sibling links.

### **[www.wch.sa.gov.au/sibling/](http://www.wch.sa.gov.au/sibling/)**

An Australian site managed by Kate Strohm who runs the Sibling Project in South Australia. Information and resources, as well as discussion groups for children, adolescents and adult siblings and professionals who work with families with a child with a disability.

### **[www.seattlechildrens.org/parents/sibsupp.htm](http://www.seattlechildrens.org/parents/sibsupp.htm)**

An American site that has adult and child discussion groups.

### **[www.siblingsofautism.com/](http://www.siblingsofautism.com/)**

### **[http://kidshealth.org/kid/feeling/home\\_family/stepsiblings.html](http://kidshealth.org/kid/feeling/home_family/stepsiblings.html)**

These sites are for young siblings and are disability specific.

### **[www.girlpower.gov/girlarea/bodywise/disability/matters/sibs.htm](http://www.girlpower.gov/girlarea/bodywise/disability/matters/sibs.htm)**

A site for the adolescent female sibling with a disability or illness.

### **[www.faculty.fairfield.edu/fleitas/sibteens.html](http://www.faculty.fairfield.edu/fleitas/sibteens.html) and [www.juliesplace.com/](http://www.juliesplace.com/)**

For young siblings whose brother or sister has a chronic illness.

# Notes

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