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Helping Kids Learn

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Information Sheet 22

Siblings of children with special needs

By Kate Strohm, Executive Director, Siblings Australia*

We have reprinted this article by Kate Strohm with her kind permission. The article outlines some of the feelings that siblings of children with special needs may have and how they may react. Many of these are negative. We hope this article helps families and professionals better understand what may be happening for some siblings. We also hope this article will give some families a starting point for discussion so they can strengthen their relationships and find opportunities to celebrate what makes each family unique. The article also discusses how the child's community influences their relationships as well as gives ideas to support siblings within their family and the community.

There are over 200,000 people under 25 with significant disability or chronic illness in Australia and we could reasonably suppose that each of these children has on average one sibling.

The sibling relationship is often the longest of any personal relationship, but with the main focus on families being toward parents (in particular, mothers) of a child with special needs, siblings are very much overlooked, not only in relation to their own mental health but also in relation to the contribution they make to the well being of a child with special needs.

Why wouldn't we be concerned about siblings? Let me share two stories that highlight this.

The first is actually a quote from a young woman recalling aspects of her childhood, growing up with a brother with special needs.

'Tara', now in her twenties and with a successful social work career, also talks of her ongoing struggles with eating disorders and depression in adulthood. She has been suicidal.

As a child, 'Tara' was unable to gain support to deal with her feelings and her well being then has had a marked effect on her emotional and mental health as an adult.

There were times at night when I would listen to my mother read to my brother in the next room. I would hear the machinery helping him to breathe and tense at every break in the rhythm.

I was not allowed to go into his room at those times.

I suppose mum thought she was protecting me. In reality I would curl into a small ball and cry endlessly, wishing myself far away,

wishing for mum to read to me, wishing for a time where

I could be hugged and wanted around.

('Tara', quoted in Strohm, K.E. (2002) Siblings: Brothers and Sisters of Children with Special Needs. Adelaide: Wakefield Press page 36.)

Learning Links is a non-profit charity assisting children who have difficulty learning and their families.

We raise funds to help children from birth to 18 years by offering a range of services including the following.

Early Childhood Services for children from birth to six years.

- Early childhood intervention and support for very young children.
- An inclusive preschool for children with and without special needs.
- An assessment and consultancy service for families who are concerned about their young child's development.
- Specialist early childhood teaching and therapy.

School Age Services for children from Kindergarten to Year 12 who have low support needs.

- Comprehensive assessments.
- Small group tuition and therapy.
- Occupational and speech therapy programs combining specialist education services and therapy.
- Outreach programs.
- The Ronald McDonald Learning Program for seriously ill children and the Reading for Life Program for children falling behind in their reading.

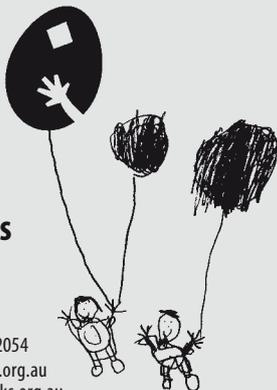
Family Services helping and supporting families and health professionals.

- Centre and home-based family counselling.
- Parenting Programs and groups for families.
- Case Management Services.

Professional Development for teachers and health professionals.

Presentations, workshops and advice on identifying and helping children with learning difficulties, learning disabilities and developmental delays.

Learning Links has branches in six Sydney locations at Peakhurst, Penshurst, Fairfield, Miller, Dee Why and Randwick. We also offer some services to children in country NSW, the ACT, Victoria and New Zealand. A complete list of branch locations and contact numbers is on the back cover.



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The other story involves a man I met at dinner one night.

He was a sibling to a woman with Down syndrome. At the time I was in the middle of writing my book and I was quite excited to meet a man who was a sibling and who might contribute to the book. Most contributors had been either mothers or sisters. As time went on it became clear that it was going to be too difficult for him to be involved.

He admitted he had left the State in which he had spent his childhood. Being a sibling and all that it entailed was just too hard for him and he had escaped, distancing himself from his family.

I couldn't help thinking that if he had been supported as a child and a sibling, it is likely that he would have been happier and more at peace as an adult. He might have had a relationship with his sister but, more importantly, she would have had a relationship with him. As it was they both missed out.

Whenever we talk about early intervention for children with special needs we *have* to consider the *whole* family.

We don't need to 'pathologise' the sibling experience but we do need to recognise the stresses involved and work towards enabling families to become stronger, more able to support each other within the family and more able to access support from outside the family.

Sibling relationships

Take a moment to think about your own sibling relationships and the influence they had on your own development.

Most times, through siblings, children learn to openly express a range of emotions, including love, loyalty, anger and rivalry. They gain companionship and support and learn to give and take. Siblings help teach each other social skills and play a part in each other's identity development. When one sibling has special needs, some aspects of the relationship can change enormously.

Issues for siblings of children with special needs

Research indicates that siblings of children with special needs (disability and/or chronic illness) often grow up in a situation of considerable stress, but without the cognitive and emotional maturity to deal with their experiences. They can be confused by their reactions.

On the one hand, a child may feel loving and protective toward their brother or sister. At the same time, they may feel resentment, embarrassment, guilt, sorrow and fear.

Without the skills to understand and deal with those feelings, and without outlets for expressing those feelings, a child's self esteem can suffer. Anger and guilt can turn inward and lead to shame and a sense of worthlessness. Longer-term problems such as depression, anxiety and somatic complaints can then follow.

However, if siblings are supported not only can their self esteem and sense of competence be enhanced; they can also develop a range of positive qualities, such as compassion, tolerance, and maturity.

Some specific concerns include the following.

Feelings of isolation

Siblings can feel isolated and different from those around them.

Their life seems different from that of their friends. They may be unable to interact in the usual way with a brother or sister with special needs. It may be impossible to give and receive affection, play together and share other aspects of a sibling relationship. It may be difficult to talk to parents – siblings may not want to bother parents who are dealing with other problems and they can feel guilty for complaining.

Most times it is difficult to talk to friends about what it is like to have a brother or sister with disabilities, as they feel their friends may not understand.

The community in general gives the message that these children should have only very positive feelings and if a child does not share the 'warm fuzzies' he or she can feel even more different and isolated.

Many siblings have their first contact with other siblings well into adulthood and for many it brings a huge outpouring of emotion as well as enormous relief to realise they are not alone in their feelings.

Lack of information

This can lead to misunderstandings about the disability and fears that they may have caused the disability or that they too will become just like their brother or sister.

They may not know how to explain the disability to others. One young girl thought that her brother playing with her hat had caused his first seizure. She never let him play with anything of her's again.

Attention

Often siblings consider their feelings do not matter to the rest of the family.

A child with a disability or chronic illness may require a huge amount of attention and energy from parents to ensure they get the necessary care. As a result, young siblings can feel left out or even neglected. They often perceive the needs of a brother or sister as being more important.

Relationship issues

Sometimes parents are struggling with their own emotional responses.

This can lead to problems in the sibling/parent relationship, which can in turn lead to children lacking confidence in that relationship and in themselves. In some situations, parents rely on the child who is a sibling for their own emotional support.

Anger and resentment

This builds up when family routines are disrupted and when the child with special needs is treated differently.

Not only does the child with special needs receive more attention, but sometimes he or she is allowed to behave in ways the sibling is not, such as acting out or breaking family rules, and it all seems so unfair. There can be anger at the child with special needs and parents, but also at other people outside the family who cause a sibling to feel uncomfortable by staring or teasing.

Embarrassment

There can be acute embarrassment about a brother or sister's appearance or behaviour, especially in public and when others tease or stare.

They may feel embarrassed about duties at home that peers don't have, eg bathing and changing nappies, especially if the child with special needs is older.

Fear

Siblings may have fears of developing special needs themselves.

There can also be fear of the physical strength of a brother or sister. In extreme cases siblings may fear for their own safety. Other siblings may be fearful about what might happen to a brother or sister with special needs, especially during crises, for example during hospital stays.

Grief

As well as feelings of sorrow for what a brother or sister deals with, there can be feelings of loss and longing for a 'normal' brother or sister, especially if there are no other children in the family.

The grief associated with disability is largely unrecognised. Parents of children with special needs have little support in acknowledging and dealing with their grief. It can be even more difficult for siblings to understand those feelings or know how to deal with them.

Pressure to be perfect

In order to gain attention, siblings may feel they have to be perfect, or at least to be successful.

They may also feel they need to be the 'good' child, to not 'make waves', in order to protect parents from further distress.

They may worry about how parents are coping. They may also feel they need to achieve in academics or sport to make up for the limitations of the child with special needs.

Guilt

Siblings may experience guilt because they do not have special needs ('survivor guilt').

There can be guilt about their own successes when they see a brother or sister struggling with basic living; about typical sibling conflicts; and also shame about the negative feelings they experience toward a brother or sister.

No outlet for feelings

Without the means to express and validate their feelings, siblings can turn the feelings inward, leading to low self worth and longer-term emotional problems.

Caregiving and responsibility

Some children take on significant responsibilities.

In some instances this can be very healthy, but sometimes these children feel they have no choice or they are attempting to appease the guilt they feel, or win parental attention or praise.

In the process, they can miss out on the usual socialising activities of their peers.

For some siblings, it can be difficult to participate in outside activities. It may be that parents are too stretched for time or the special needs of a child may be too unpredictable for parents to feel able to fit in regular commitments like ballet classes, sport, or music lessons.

The child can feel enormous conflict between caring for a sibling, feeling guilt and resenting missing other activities. This can hinder the normal processes of identity development.

Independence

As they move into teenage years, siblings can find it difficult to go through the usual process of separation from their family.

Some families can become very close through the experiences they share, which can be a positive thing. However, if the closeness and sense of responsibility becomes out of balance, a sibling can really struggle to gain independence.

The Future

A sibling can have concerns about the future, both for themselves and their brother or sister with special needs.

What will happen when parents are no longer able to provide care? What role should the sibling play? Will they be able to find a partner in life who will take on the responsibility of someone with special needs? What about having children themselves? What if the disability strikes again? How can a sibling balance the responsibility to their own family and a brother or sister with special needs?

How sibling concerns manifest

The many and varied pressures on siblings can lead to a range of reactions which, if not addressed, can carry forward into adulthood.

As young siblings may not have developed the cognitive and emotional maturity to understand, express or cope with their feelings, those feelings may prompt other difficult behaviour or responses. Some of the more common forms of behaviour seen through the Sibling Project and other services are described here, along with a few examples.



Withdrawal

Some children withdraw into themselves in an effort to escape the stress. They may neither feel able to influence what happens, nor express any concerns.

Susie withdraws to her room each time her older brother with autism goes into a rage. She worries about whether things will be damaged and the safety of her mother. She is becoming increasingly anxious and is learning a particular way of dealing with stress that might not be healthy in the longer-term.

'Acting out'

The child with special needs may require a lot of attention.

Siblings may feel that they miss out on attention and use various behaviours to try to gain attention. They might 'act up'.

Mitchell is in trouble all the time. He has a younger brother with disabilities and feels that his parents only have time for him. He says, "All they ever think about is him. I never do anything with mum and dad. I could before he was born. They like him better than me and buy him lots of things." He actually shows considerable care toward his brother but receives no acknowledgment for that. When asked what he would do if he had a magic wand he said very calmly, "Shoot him".

Victoria was in and out of child mental health services due to excessively disruptive behaviour at school and home. At age eight she was prescribed antidepressants by a private psychiatrist. Her sister has autism and poorly managed diabetes. While she worries about her sister's welfare, she also resents the fact that her sister is treated as being much more important in the family.

People pleaser/perfectionism

A sibling might become a people pleaser, the 'good child'.

Some children will become a compulsive helper, not only to gain attention but also in an attempt to make things right for parents who they see as dealing with a lot of stress. They might feel that everything they do has to be perfect, leading to a feeling that they are never good enough.

Josie, now an adult, says, "I was told what a good child I was every day of my life". She lived her life as the perfect child, putting enormous pressure on herself, afraid to disappoint anyone. As a young child she would worry about dying young and leaving her parents and brother alone.

Anxiety/depression

Children can experience a range of anxieties, not only about the child with special needs but also about themselves.

They may fear that they too will develop special needs or they might blame themselves for a brother or sister developing special needs. As a result they might develop longer-term anxiety or depression. The anxiety might manifest in sleep problems, nightmares, or somatic complaints like stomachaches. Some siblings develop eating disorders.

One mother, referring to her daughter, said, "She's a mess at school the days her sister is in hospital". In spite of this girl showing a range of anxious behaviours, her over-stretched mother relies on this child for her own emotional sustenance.

Social difficulties

We learn much about interacting socially from our brothers and sisters. When a child has a disability this social learning by a sibling can be significantly compromised.

Emily lives with her older brother with autism and struggles with social interactions in her peer group. Many of the ways of interacting she is learning from her brother are not appropriate for her friendships. In addition, family life is hindered. She had her first holiday away from home with her parents at the age of 11. They were able to find some respite with family for their son and brother and for two days they were able to share some rare and peaceful time together on a houseboat.

Impact on a child's well being

It is easy to see how the above scenarios can impact on a child's well being.

There is not room in this paper to discuss details, but some of the children above have had access to support through the Sibling Project.

Intervention with Victoria and her family made a marked difference to the way in which they interacted. This involved the family understanding how to support each other and how to access support outside the family. Apart from anything else, Victoria felt very important having her own 'special' appointment with us.

This would be followed up by lunch with mum. Not only did Victoria's behaviour improve markedly but also the special needs of her sister were managed much more positively. The intervention was carried out over several months but was neither complex nor demanding.

Possible positives

If siblings are supported, they can become stronger and more resilient in dealing with their difficult experiences.

In the longer-term, siblings can develop a range of positive qualities such as tolerance and compassion, insight and maturity, responsibility and pride in a brother or sister's achievements.

There is anecdotal evidence to suggest many siblings go into the helping professions, which can seem a natural progression from the responsibilities they assumed whilst growing up. This can be very positive for the community but also for the sibling, if their own needs are not compromised in doing so.

Factors affecting adjustment

What makes the difference between a positive and a negative experience for siblings?

Unfortunately, this is a rather complex matter, but there are many factors that can be influenced by various interventions.

It must be remembered that there is a limited capacity to change some factors such as the socioeconomic status of a family, the type and severity of the special needs, the number of siblings in the family, whether one or two parents are involved in the family.

Clearly, it is important to consider these factors as well when assessing the needs of a sibling. For example, a sibling who has no other brothers or sisters aside from the one with special needs might have certain needs relating to social skills.

The diagram below summarises the main relationships or settings that can influence how a sibling perceives their situation, and from that, how he or she adjusts. The interactions can be both risk factors and protective factors. These interactions also highlight possible areas for intervention, which I will discuss below.

The sibling

A child's own personality and temperament, their innate physical and emotional make-up will influence how a child reacts to situations.

For example, some children are naturally more sensitive or anxious. At the same time, a child's perception of self (eg self-esteem) and sense of competence will influence a child's 'self talk' which, in turn, affects their way of operating in the world. Much of that perception of self is influenced by the relationships a child forms with others.

Interaction with the child with special needs

Some children with special needs can be quite aggressive which can lead to difficult interactions. Others might not have the ability to communicate, again hindering the interaction or development of a relationship. On the other hand, even when communication is limited, a strong sibling relationship can still develop.

Interaction with parents

Parents' adjustment and how they express feelings or convey information can be a big factor.

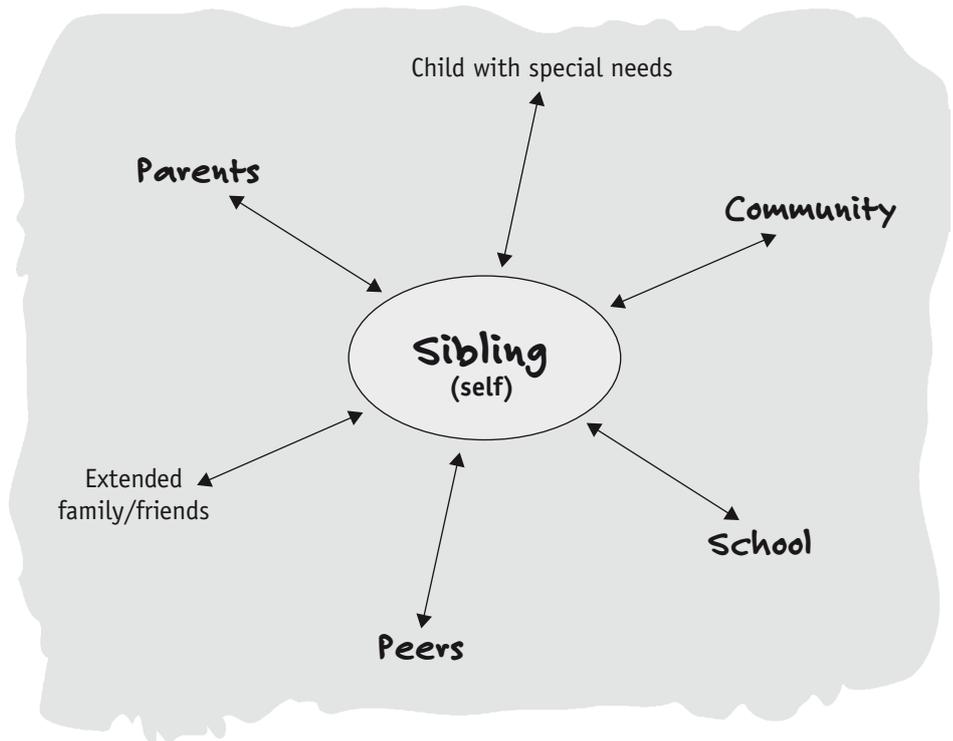
The meaning that parents assign to the special needs of a child will influence how a sibling views what is happening within his or her family.

Some parents see having a child with special needs as a punishment, while others see it as a blessing or as a challenge, and this will influence the messages they give to their children.

The relationship between parents and siblings can be compromised when a parent needs to devote time and energy to a child with special needs. In some cases, the relationship is compromised even further if the parent(s) still struggle with their own grief and other feelings.

One parent said in relation to her eight-year-old child "I tell her regularly she should feel lucky because she doesn't have special needs like her brother". This will inhibit that child ever discussing any difficult feelings.

Some parents have very different expectations for the child with special needs than they do for the sibling(s). Other parents might hide the true diagnosis from siblings in an effort to protect them. At the same time, siblings might want to protect parents who they see as being vulnerable and stressed.



Communication can be difficult in such families and some siblings have talked of growing up in a situation where the whole family was "walking on eggshells".

Interaction with others

For some siblings, social interaction with peers may be difficult, either through difficulties in their own social skills or because it is difficult to have playtime at home with the extra demands placed on the family.

Extended family or friends, peers, school, community and social support in general will influence a sibling's sense of value about himself and his family.

The messages given by others will influence the meaning a sibling gives to the special needs and these messages can often be conflicting.

On the one hand a child might be told how special they are to have such a special child to care for, yet the child will also likely experience the stares and teasing directed at the sibling or the child with special needs.

School

Many siblings' own social needs can be compromised if a brother or sister attends the same school. There may be teasing or other difficult situations.

The level of awareness amongst school staff will also affect how much support is available. There is a range of possible interventions, either as part of existing programs, such as bullying, or as an adjunct to those. Informal measures can also be important. If the child with special needs attends a different school, siblings can still gain support through their school. Currently, there are few, if any, specific interventions in this setting.

Community

Social support in general will influence whether a family as a whole feels isolated or part of a caring community.

Some support organisations – disability, health – take a broader whole family approach. When this occurs, siblings are more able to access support from the same service that works with the child with special needs. Counselling services, sibling groups etc can all affect how well a sibling adjusts.

Historically these services have been slow to embrace the whole family. Certainly, if siblings do show symptoms of concerns, a lack of understanding by providers can compromise the support that is available.

Clearly, in looking at what factors affect adjustment, it is crucial to take a systemic approach, exploring the family 'system' and the broader community 'system' that impacts on and influences a sibling's reaction to what is occurring around them.



What parents need

Before we look at supporting siblings it is important to consider what parents need.

Only when parents have their own needs met are they fully able to respond to their children who are siblings. Parents need to have their grief recognised and validated. They need to accept and communicate their feelings around what has happened. They may feel out of control and need to learn ways of feeling competent and more in control.

One social worker is quoted as saying, *“Parents should just see this as a bump in the road”*. This type of response negates the reality.

Before anyone can move forward positively, they need to understand and acknowledge the feelings and reactions they experience. A strengths-based approach is to be promoted, but that needs to be alongside an acknowledgment of and respect for the reality. It is crucial that support comes early to all members of a family where a child has special needs. If parents are able to access support, they can more easily support their children.

The meaning parents assign to the special needs influences how they react and move forward. Creating new meanings can be a major task of the journey and needs ultimately to come from within. Social support from extended family and friends, and the broader community, can help families move to more positive meanings and give value to the child with special needs and the family as a whole.

Parents also need practical resources and access to good respite care.

What siblings need

It is important to ensure that support is available in the different settings in which siblings live and play, such as their family, with friends, at school and in the community.

Within the family, siblings need to have clear information and to be involved in decision-making. They might need help in interacting with a brother or sister with special needs.

They need to be able to identify and express the good feelings and the not so good feelings and to feel comfortable with the mixture of feelings they might have and to understand where they come from.

With so much attention being given to the child with special needs, siblings need to feel special too and have time put aside for them. They also need to feel valued for any contributions they make to the family. They need to feel competent and capable and learn skills to deal with their different experiences and to develop independence.

Social support from extended family and friends can help siblings feel valued and less isolated. As well, specific purpose groups in which siblings come together to have fun and share experiences can be a very valuable and powerful tool in giving siblings support. As one young sibling said of the group, *“at least I have somewhere I can talk about things now”*.

Why siblings are overlooked

When it comes to addressing the needs of young people, this group of children is often overlooked with little attention given to their needs through the disability, health or education sectors.

It is relatively easy to understand the difficulties for a young child who is abused or has a parent with drug dependency or mental illness. It is less clear what the impacts are of having a brother or sister with special needs.

Part of the difficulty is the wide variety of experiences. Some siblings have very positive experiences, others very negative and some have a mixture of both. However, it is mainly the positive experiences that are highlighted in our culture, and it is easy to generalise these stories to the wider community of siblings.

There seem to be three main reasons why siblings are overlooked.

1. Siblings can find it difficult to express their concerns. Who are they to complain when a brother or sister is struggling with basic living skills? How can they add to the burden of already stretched parents?

Often, as mentioned earlier, they are given the message that they have been specially chosen to care for the ‘special’ child, or that they have to be a ‘good girl’ or ‘good boy’ because ‘mummy and daddy have a lot to deal with’. There can be confusion about the feelings they do experience; they might love and care for a brother or sister with special needs but they might feel sadness, loss, resentment and guilt. It can be difficult to express such feelings even if they are given permission.

2. Within a family, the needs of a sibling can be overlooked as parents try to cope with their own feelings and reactions. Sometimes a parent will recognise that a sibling is having difficulty, but their own emotional resources are too stretched to act on their concerns. They might be still struggling with their own grief and sense of loss of control.

Some of the children we have seen have struggled because their parents have not received the support they needed in the early stages following diagnosis. As a result, the relationship between parents and a sibling might be compromised.

3. Often providers fail to recognise the issues for siblings. Siblings might present as the good child or their behaviour may be dismissed merely as attention seeking without exploring why that is so. As previously mentioned, there is little awareness amongst professionals of the struggles for siblings because it is the positive stories that are focussed on. Another issue is the question of whose responsibility are these children. Should they come under the mental health area, or disability, or education?

One of the difficulties with aiming for an integrated approach is the fact that responsibility for the welfare of families and children is spread over many different departments, in both State and Commonwealth governments.

Role of parents

We can’t assume all problems are a result of being a sibling, but we need to be alert to signs that a child might be feeling some anxiety or discomfort.

As a parent, ask yourself whether the sibling is able to respond to questions from others about his brother or sister with special needs.

Does he/she sometimes choose to spend time with a brother or sister? Have regular time alone with one or both parents? Have friends come to play? Enjoy school? Does he/she take on too much responsibility? Have sleeping problems, or ongoing stomachaches or headaches? Does he/she have contact with other siblings?

Some of the key ways of supporting siblings include giving them information, listening to them and helping them express their feelings. Parents can give children 'permission' to express their feelings, and set an example by showing it is ok to share difficult feelings.

Watch for behaviour that might indicate stress and help them learn skills to deal with difficult situations. Spend one-on-one time with a sibling to help them feel special too. Acknowledge their contributions to household activities but avoid giving them too much responsibility. Encourage siblings to have contact with other siblings, either through groups or the internet.

One young mother meets a group of other mothers, along with the siblings, once a month for informal recreational activities. Even if no one else joins them, this mother and her daughter have a regular time together.

Resources are available through Siblings Australia to help parents in their role of supporting siblings.

Role of service providers

The role of service providers is to help families become stronger. It involves helping parents support their children but also enabling siblings to have direct access to support services.

There is a range of ways providers can work with families.

These might include working with parents individually to address critical issues and to focus on how they can support all their children. We can have parents come together in groups. We can work with parents and siblings together, so they can learn how they can support each other and access support elsewhere. We can work with siblings individually – to address their needs and help them become stronger. And we can work with siblings in groups. Finally we need to ensure that we work with disability organisations, schools and other community groups.

Let me share a story which highlights one way providers and parents can work together.

At a workshop one parent talked about her concerns about the therapy sessions for her son, Jamie, who is two years of age, with an early intervention worker.

His older sister, Susie, who is four, tends to get in the way. She wants to play with all the toys and tries to be involved.

The mother found it difficult to get Susie to leave things alone and do something else.

It is understandable that this mother is concerned that the little boy gets as much value from his limited time with the therapist, to enhance his development. However, it is also understandable that this little girl is attracted to what is happening. Her brother is the centre of attention and the activities and toys look so interesting. How can we adapt what is happening to make sure everyone's needs are met?

Perhaps the early intervention worker could spend just a few minutes with Susie showing an interest in her, asking about what she has been doing at kindergarten etc, showing her the toys.

Maybe Susie could be given a set task as part of Jamie's therapy. If he needs help in putting a yellow peg into a green hole, that could be her job. She can be valued and appreciated for being a part of the treatment team. The worker can help Susie to do other fun things with her brother. Ultimately these sorts of activities will likely assist the longer-term relationship between the two children.

It is important to not overdo such responsibility, but in balance such involvement can add to the sibling's sense of worth and also encourage family relationships. The worker can also talk about other ways in which the parent can support the sibling(s).

When to intervene

We have discussed ways of supporting siblings but *when* should we intervene?

We need to think seriously about the support needed by families very early on, at diagnosis even.

Are we helping parents deal with their own issues around loss and grief? Are we helping them to support each other and in the process strengthen their relationship?

Many marriages break down under the stress – are we doing enough to prevent this? Are government family interventions doing enough in this area? Are we supporting the *whole* family from the very beginning?

There has been considerable activity in developing support groups for siblings.

This is a wonderful development and one that provides enormous benefit to children. But we need to put as much energy into supporting and strengthening families as early as possible.

Where to from here?

In recent years, there has been a growing number of programs, both here and in the United States, that address the needs of siblings. Most of these have relied mainly on the commitment of individual service providers or organisations. Instead, there needs to be more collaborative effort so that resources and skills can be shared.

There needs to be more research into what helps families become stronger and more able to support each other, and on risk and protection factors.

We need to explore how we might best support siblings in school – whether their brother or sister attends the same school or not. This involves finding ways to increase schools' capacity to support students and maximise their development.

We need to make sure that sibling support is placed on the political agenda.

A Final Word

What can you do as an individual?

Try to improve your own awareness of sibling issues. Access the website of Siblings Australia and read some of the listed books or journal articles and other information, including annual reports of activities.

If you're a provider, create a 'siblings' file in your filing cabinet.

Respect siblings' experiences. Give them a voice, be a witness. Acknowledge the difficulties while giving them skills to become stronger in dealing with their experiences.

Connect with others who are interested in sibling support. Share resources and skills. Join SibServices, the internet discussion group for people running or planning sibling programs. Join Siblings Australia to help further this work.

Share the web address with other colleagues and families. Connect siblings with other siblings.



Encourage siblings to connect with each other through the discussion groups available on the Siblings Australia website.

Advocate for the needs of siblings, not only in local organisations, but also at a broader political level.

It is important that we all work together to keep family and sibling support on the agenda. We have just begun.

**This article is sourced from a Keynote Paper presented by Kate Strohm at the 18th Early Childhood Intervention Association (NSW Chapter) Conference 'Made in Australia – Research and Practice' August 2003. Much of the content of the paper is based on interviews with siblings conducted during the course of writing her book 'Siblings: Brothers and Sisters of Children with Special Needs' and through consultations undertaken through the Sibling Project, established in 1999 in the Department of Psychological Medicine at the Women's and Children's Hospital in Adelaide. Kate is Director of Siblings Australia and we have reprinted this article with her kind permission.*

Siblings Australia

Siblings – Acknowledged, Connected, Resilient

Siblings Australia's mission is based on the following principles:

- **Whole family approach**

Traditionally, services have focused on the identified patient or client. Even when a family perspective is taken, often the focus is on parents (usually the mother) and the child with special needs, with insufficient attention given to siblings (and fathers). What happens to one family member clearly impacts on all the others – we can no longer talk of family members in isolation.

Research indicates that other family members may, at times, experience greater stress than the person with special health needs. Families in this situation can be vulnerable to maladjustment, the possibility of marital breakdown and increased use of psychological services. The quality of life for a family in this situation is very much influenced by the degree of support they are offered, especially in the early stages. There is a need to identify processes that provide positive outcomes for adjustment for the whole family.

We must remember, too, that if we support the family, ultimately we are supporting the person with special needs.

One family of a child with a terminal illness was given a trip to the Gold Coast through a charity organisation. When the mother asked if the child's brother could also swim with the dolphins, a health professional replied, "Oh no, that's just for the special child". Does this approach meet the needs of the whole family?

- **Family-centred care**

Family-centred care involves a shift from the traditional 'professional as expert' model to recognition that families have much to contribute when decisions are being made about their child and family. By focussing on family strengths, service providers can assist families to feel more competent and able to support all members of the family. Families can learn how to support each other within the family and also how to access support outside the family. Families can develop a much stronger sense of control.

- **Prevention**

Many child health services continue to focus on 'fixing' problem behaviour. In recent times, however, there has been much emphasis on early intervention and the identification of children who are at risk of developing mental health problems. Siblings of people with disabilities often grow up in a stressful environment, and often without the cognitive and coping skills to deal with their experiences. These children fit in to an at risk category.

Services need to have a more preventative approach whereby children are given the skills to deal with their experiences and are able to grow up feeling strong and competent. Intervention with siblings at a young age is not a difficult task and it takes few resources. However without intervention, the psychological cost to the sibling and the cost to social services in later years can be high. At the very least we should be attempting to put siblings in touch with each other.

In its current form, Siblings Australia provides counselling for families, runs parent information sessions, compiles related information and resources, provides training and support to service providers, including training for running sibling groups.

It also manages a website with related links and opportunities for siblings and providers to network, supports research and has formed networks with both hospital and community bodies around Australia and overseas.

During the last 18 months separate workshops have been conducted for parents and service providers in Adelaide, Sydney, Melbourne, Warrnambool, Echuca, Brisbane, Ballina, Coffs Harbour, Armidale, Brisbane, Perth, Canberra, Albury-Wodonga and Wagga Wagga. Many hundreds of people around the country have shown enormous interest in sibling support.

This year Siblings Australia is planning a national conference in Adelaide – details are on their website – www.siblingsaustralia.org.au. They hope to make contact with many people who are interested in sibling issues.

Siblings Australia, like Learning Links, has difficulty accessing funds. Siblings Australia is hoping to develop a large membership base and increase its funding to take its work further.



My brother or sister has special needs, what about me?

By Sandra Samuel, Family Counsellor

When dealing with a child with special needs, it's difficult to manage the different priorities of every family member.

How do we accommodate everyone's needs in a family when by necessity many of the decisions of the family revolve around the illness or disability of a child?

How do siblings react to the stresses involved and just what is their relationship with their brother or sister with special needs?

The issues that face siblings of children with special needs vary according to the extent and type of disability or illness.

There are many different types of special needs – children with learning disabilities, global delays, congenital disabilities (or syndromes), chronic illnesses and those who have experienced sudden illness as a result of an accident or trauma which leads to a disability. Each situation has its own unique circumstances and challenges for both parents and other children in the family.

Sibling relationships

Sibling relationships provide significant social experiences for children.

Because of shared family experiences, some brothers and sisters play an important part in each other's lives and maintain close relationships into adult life. Others are not close at all, while some grow apart as they get older.

Relationships between siblings when a brother or sister has a disability or illness can be the same as those between any siblings; they can be close, distant or anywhere in between. A disability or illness is only one of a number of factors that determine the nature of the relationship between brothers and sisters.

Because an illness or disability can cause considerable financial, emotional and often physical strain on a family, it can also strain relationships between brothers and sisters as they experience the many varied and quite natural emotions associated with their situation.

Siblings can often feel guilty about being healthy, embarrassed by how their brother or sister looks or acts, scared that they may become ill or disabled in the same way, and isolated from friends who may not understand. They can also feel that they have to do exceptionally well to make up for their brother or sister.

Family relationships

Families with children with special needs often find their relationships with others outside the family are affected by their situation.

Caring for an ill or disabled child can lead to social isolation or social contact limited to other families in a similar situation. Understandably, this can have an effect on the other children in the family, even more so if the illness is sudden and quick changes to lifestyle and routine need to be made.

Where a child has a chronic illness or disability, the other children in the family usually become aware of any isolation and they perceive that the illness or disability forms the basis for the family's way of life. A lot of communication within the family can revolve around the child with the disability or serious illness, further focussing on the illness or disability.

Agencies and professionals assisting the child and the family may impose extra pressures with inflexible appointments, clinics or treatment schedules.

Relationships between family members are often affected by the failure to clearly articulate to siblings the special needs of the child, whether it is a disability or illness. This can lead to the family hiding thoughts and feelings from others.

Often there is less supervision for siblings due to the needs of the child with a disability or illness. This can mean more responsibilities and jobs at home.

Siblings may also experience a parent's anxiety and absence.

When a seriously ill child needs to be away from the family and in hospital for lengthy stays, one parent will often stay at the hospital with the sick child.

This can lead to feelings of abandonment or jealousy in the children who remain at home and be exacerbated by the fact that parents of children with illnesses or disabilities often find it difficult to relax and have fun with their children. Time constraints and exhaustion are ongoing issues.

For some children, hospital stays can be unexpected or erratic, leading to less planning for family holidays and special events. Siblings often just have to fit in.

Financially the burden can be no less severe. Paying for activities such as sports and hobbies may be more difficult due to the expenses associated with a child's special needs. Stretched financial (and energy) resources can mean limited opportunities for siblings to pursue hobbies, sports and other events outside the family.

As difficult as it can be for the family as a whole, the reality is that many decisions within a family have to be made in relation to the child with special needs.

It is not surprising that sibling rivalry and hostility are often exacerbated where there is a child with special needs, which in turn leads to additional stress on an already overloaded family.

Too much stress over a long period of time may adversely affect cognitive functioning and academic performance, hence it is important to do as much as possible to reduce tension.



It's not all bad!

It's easy to highlight the negatives, but to keep the situation in perspective, there are also some wonderful positives as well.

Siblings of children with special needs tend to have increased empathy, tolerance, and compassion – all qualities we admire and need in ourselves.

Because of additional responsibilities, they can also be more self-confident and independent.

They tend to be more adaptable and have good problem-solving skills and often have a good knowledge of a wide range of topics, particularly related to medical issues.

In larger families siblings support each other and share extra jobs and supervision. This can bind them closer together as they share the ups and downs of the situation.

As a parent, what can I do?

There are a number of things you can do to help your other children in a family with a child with special needs.

- Ensure some special time with each of your children.
- It's O.K. not to be able to do everything yourselves.
- Use available respite care wherever possible to spend valuable time with your other children and as down time for yourself. Accept offers of help from relatives and friends to maintain activities with your children and to help with the child with special needs.
- Ensure you remind yourself that your children are still children and should not take on responsibilities that they can not handle.
- Talk openly about what it feels like to have a brother or sister with an illness or disability. Listen to what they say and understand that their feelings are normal. Give them permission to be embarrassed, guilty, angry, resentful, or whatever they are feeling.
- Include siblings when making family decisions, asking and respecting their opinions.
- Explain the illness or disability, talking honestly about the effects on the family and the family's responsibilities.
- Make sure you repeat discussions if your children don't understand the illness or disability at first. Keep them regularly updated with new information.
- Help your children understand that they have a right to have their own friends and pursue their own hobbies and dreams.
- Don't assume that every problem your children and family deal with is due to the demands of your child with special needs.
- Let them be kids; let them fight sometimes; let them enjoy growing up.



www.learninglinks.org.au

Early Childhood Services

– all enquiries to Head Office

School Age Services

– contact your local branch

Family Services

– contact your local branch

All other enquiries

– Head Office

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