Siblings
Participant Notes

‘Siblings play a very special role in our lives. They are our fellow adventurers, confidantes, advocates, best friends and dire enemies! The sibling relationship is one that may last 50, 60, or 70 years. Siblings of children with special needs make a unique contribution to the family system, and, like their parents need attention, understanding and support. (McPhee & Westrup, nd, p. A-1)

Just as every family unit needs to be recognised for its uniqueness, integrity and strength, so too does each individual member.

Within the family unit siblings play a very important role in the lives of their brothers and sisters and their parents. This is true for any sibling, however the role of a sibling of a person with special needs is likely to hold much more responsibility. It is often a responsibility that develops over time supporting the parent and the sibling with special needs. It is a sibling relationship that looks very different from the usual.

As parents, it is important to reflect on the length of time that the sibling has been in this role – that is, all of their lives. The ‘world of autism’ with all of its complexities is, for the parent, taken on with an adult’s understanding. Research certainly supports the many challenges and difficulties that this poses for parents (refer to Session 3 – Day 1).

As a sibling this understanding develops over a much greater time and through different developmental levels – as a toddler, a child, an adolescent and an adult. It is important for parents to spend some time reflecting on where the sibling is, in terms of their age and development, and how this impacts on the way they view their interactions and relationships within the family.

What does life look like ‘through the eyes of the sibling’?

Parents are concerned for the support of all members of their family. They hold concerns for issues that are faced by siblings and are acutely aware of the physical, social and emotional complexities of raising a child with autism. Over the past couple of days you have been encouraged to ‘look at life through the eyes of their child with autism’ – for example, the Characteristics Matrix. Now you are going to ‘look at life through the eyes of the sibling’.

It is important to:

• take time to explore the range of feelings that can be experienced by the sibling
• recognise that some of these feelings and experiences can be part of life when living with a sibling with autism and some are part of life as any sibling
• be able to explore this without feeling overwhelmed and guilty
• recognise that these feelings are both positive and negative
• understand that these are not necessarily feelings held by all siblings all of the time
• recognise that the sibling’s understanding of autism, just as their thinking on many things, will change and develop over time

**What are common issues/difficulties for siblings?**

Take a moment to consider what life actually looks like for the sibling. As you think about it, you may find it easier to list the negative issues but try to balance this with the many positive and highly valued attributes that you may see developing in the sibling.

Some of the negative feelings/issues experienced by siblings may include:

• chaotic home life
• embarrassment
• confusion
• frustration
• dangerous situations
• angry responses
• jealousy
• attention seeking behaviour
• loneliness
• sadness
• guilt
• pressure
• a sense of responsibility
• other

Some of the positive feelings/issues experienced by siblings may include:

• caring
• nurturing
• kindness
• understanding
• tolerance
• maturity beyond their years
• independence
• strength
• flexibility
• similar caring friends
• forward thinkers
• proud
• sharing
• loving
• compassionate
• other

### Identifying a sibling's need for support

It is not necessarily the case that all siblings will experience all of these emotions with the same intensity, and they certainly won’t be experienced all of the time.

It can be difficult to look at a negative list such as the one above and not feel guilt or self doubt about your ability to parent. However it is your ability to identify the negative impact that will allow you to support all of your children. It is this awareness that will improve your ability to support. This includes your knowledge of the sibling and their usual behaviour.

‘Children can be resilient and often need very little in order to adjust positively. If you understand that siblings within your family are facing particular difficulties, both you and all your children can benefit.’ Kate Strohm (*Siblings: Brothers and sisters of children with special needs*, 2002, p. xiii).

### How do you know when things are getting too difficult?

There are various signs that indicate the sibling may be finding things too difficult and that they may need support. They may demonstrate the following:

• anger
• sadness
• fighting – verbally, physically
• being quiet
• being withdrawn
• being frightened
• feeling sick
• staying in their bedroom more
• using statements such as ‘I hate…’
• always wanting to play elsewhere, go to relatives
• avoiding their sibling with autism
• attention seeking
• teasing
• experiencing difficulties at school – academic and social
• being overly ‘good’/‘helpful’
• other

It may be difficult to identify the need for support for the sibling. This is due to:

• the day to day demands of parenting your child with autism
• not knowing what is/is not usual child behaviour at different ages

‘Each child will react differently to a brother or sister with a disability and so particular needs will be different. Each family situation is complex and the needs of the children must be explored in that context. Children’s needs change according to their stage of development. They will also go through different phases.’ Kate Strohm (Sibling: Brothers and sisters of children with special needs, 2002, p. 149)

**How do you support?**

It is important to note that the sibling is just as individual as the family unit and care must be taken when interpreting behaviour. Just as you are the ‘expert’ in identifying the characteristics and impact for your child with autism, so you are the expert for the sibling because you:

• are aware of the issues the sibling faces
• know the ways your children individually react
• know the strategies that will work for your family
‘Once parents understand the needs of siblings, it can be relatively simple to provide support to able children.... Whatever the situation, if children feel safe, supported and valued, are able to share information and feelings, and feel they can solve problems, make choices and have some control over their lives, they will develop greater self-esteem, strength and resilience.’ Kate Strohm (Sibling: Brothers and sisters of children with special needs, 2002, p. xiii).

**Strategies to support siblings:**

**Issues around time:**

- Often recognised as your ‘greatest gift’ however it is the one thing that you feel most guilty about – your lack of it due to the demands of parenting your child with an ASD.
- Your time is necessary for communication and understanding.
- Planning special activities and occasions.
- Family meetings to talk things though.
- Parent time – opportunities to spend time together or with another adult. Use relatives, friends and respite care to help make this happen.
- Consider ‘little opportunities often’ rather than big plans that sometimes go wrong or don’t happen.
- Provide age appropriate opportunities for communication within your family.

**Developing sibling knowledge:**

Just as you have increased your knowledge since your child’s diagnosis of autism, consider the same ‘thirst for knowledge’ of the sibling.

Think about providing opportunities for siblings that:

- increase their understanding about ASDs
- increase their understanding about their sibling with an ASD – characteristics, impact, strategies that work, sensory sensitivities
- create an environment where any and all questions can be asked. (There are many resources available to parents about autism and living with a sibling with autism)
- develop their understanding and ability to explain to others. It is good for them to be confident about communicating with their peers and others
- teach them what they can do when things are difficult (i.e. when there is a major tantrum happening, where they can safely store their prize possession, etc)
Things to consider when developing sibling knowledge:

- Use clear and age appropriate language.
- Talking to and telling the sibling will involve talking to and telling the child with an ASD and others.
- Check their understanding about autism. Ensure that the appropriate knowledge comes from you and not other/outside sources.
- Misinformation leads to misunderstanding and feelings of isolation and fear.
- Knowledge is power.
- Their need for knowledge will develop over time, for example, older siblings may be more interested in information about causes or have concerns about their own future children.
- Model the attitude and language you want the sibling to use but also allow them into your journey as well – be a ‘role model’ but remember you don’t have to be the ‘perfect role model’.

**Assisting siblings to understand their feelings:**

- Acknowledge and accept that there is a great range of feelings that are part of the typical sibling relationship, and relationship with a sibling with an ASD.
- Those feelings are normal and okay.
- Acknowledge and give insight into their feelings – that is, the real message. Sometimes this means translating ‘I hate...’ into ‘I know you are angry that....’ Labeling feelings helps you know how to support and not misread feelings.
- Encourage appropriate ways to express feelings without feeling bad – we do not always have good feelings about each other, do not always feel that things are fair etc.
- Discuss with the sibling ways to deal with stress.

**Think of the sibling as an individual:**

- Be aware of what is appropriate behaviour for the different developmental stages.
- Recognise the importance of identity. Identity is not defined by what they do or don’t do for their sibling with autism; it is about their qualities, attributes and achievements.
- Recognise the importance of the sibling having their own interests and activities that promote self confidence and identity.
- Have realistic expectations of siblings in terms of their relationship with all family members.
- Protect their privacy.
• Teenage years can be a time of change in relationships within families. Providing balance, support, understanding, acceptance and possibly lots of humour will assist a smooth transition to adulthood.

**Adult siblings:**

• It is important to provide a forum for open communication around long term plans.

• Be honest and open about their role in the family and any expectations you might have. The development of these plans occurs over many years.

• Because siblings find their own level of involvement in their brother or sister’s life, expectations do not necessarily become a reality.

• It is important that siblings have the knowledge, the ability and the support that is needed to take on any future role.

• Research shows that adults who take on a caring role for their sibling find support in their relationship with their parents and spouse/partners.

**Sibling Networks:**

• Investigate different types of networks that siblings can be involved in, such as family, relatives, friends, school, community and sporting groups, other siblings of children with special needs etc.

• Look at the role of relatives and friends. Discuss both the positive and negative expectations of other family members with the sibling.

• Consider the options and value of sibling camps.

• Complete the *Siblings Networking Activity* at the end of the Participant Notes to identify, explore and possibly extend current networks of support.

**School life and Expectations:**

Siblings may or may not attend the same school as their sibling with autism. It is an individual decision based on many factors such as school options, family situation, students involved and services available.

**What can we learn?**

‘…every family has a story, because every family has its own journey. And we can also learn that every sibling pair is on their own odyssey. When a sibling has an ASD, it can be a true odyssey – a long and difficult trip filled with tumult, upheaval, and intensity… No one chooses to be a sibling of a person with an ASD. However… those who do find themselves in this extraordinary role can
find meaning, inspiration and happiness in their families, for themselves, and in relationships with their siblings. Strength, compassion, and tolerance are some of the many gifts that come with the territory.’ Feiges & Weiss (2004, p. 127. *Sibling stories: Reflection on life with a brother or sister on the autism spectrum*).

**Where to from here**

Using the GROWTH model to plan strategically to support the sibling in your family will assist you to identify the major issues impacting their life. A GROWTH model is provided as an example.
**GROWTH MODEL**

*Susan is 13 years old. She has an 8 year old brother with autism. Up until the last few months, Susan has been a happy and well adjusted child. Recently, however, she has been less tolerant of her brother, provoking him by taking his favourite toy. She cries a lot and has been yelling at her mother and father. She says they don’t love her anymore.*

<table>
<thead>
<tr>
<th>G</th>
<th>For Susan to feel more loved and valued.</th>
</tr>
</thead>
<tbody>
<tr>
<td>R</td>
<td>Susan is 13 years old. She is going through puberty. She says she doesn’t feel loved and cries a lot. She yells at her parents and has become intolerant of her brother.</td>
</tr>
<tr>
<td>O</td>
<td>Acknowledge her feelings. Provide the opportunity to express her feelings to you privately. Spend some quality time with her doing something she really enjoys. Tell her you love her. Encourage her to tell you what life is like for her. Be aware that some of this behaviour is age appropriate and due to the impact of hormonal changes. Ensure that she has a good understanding of her sibling. Identify current support networks and extend if necessary.</td>
</tr>
<tr>
<td>W</td>
<td>Plan an outing with Susan.</td>
</tr>
<tr>
<td>T</td>
<td>Make a date with her. Plan what you are going to do together. Ensure there is some time to walk together or do an activity that provides a forum to talk. Validate her feelings. Talk about the people around her that are also able to support her.</td>
</tr>
<tr>
<td>H</td>
<td>Plan to get together regularly. Go for a walk together regularly to give her an opportunity to off load her thoughts. Involve her in some planning for strategies for her brother.</td>
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</tbody>
</table>
Close relationships:
- family – other siblings, grandparents, aunts, uncles, cousins
- boyfriends/girlfriends
- good friends

Informal relationships:
- sibling support groups, fun days, sibling camps
- family days at your child with autism school/organisation
- family days organised by parent support group
- friends, mentors at school
- neighbours – children, adults
- youth/church groups – leaders and members

Professional relationships:
- leisure activity groups – leaders and members
- sport activity groups – coaches, managers and members
- study tutors
- school principal
- school staff
- school counsellor
- psychologist
- local GP/medical professionals
- respite care agencies
- Siblings Australia
  www.siblingsaustralia.org.au
Information about ASDs for Siblings

Websites

• www.cyh.com
  Information resource
  Enter through kids health (6-12 year olds) or teen health (12-17 year olds) then search autism or Asperger syndrome.

• www.nas.org.uk
  UK resource providing information and real life stories
  Double click on ‘Information for...’ in task bar on left hand side then ‘Siblings’.

• www.siblingsaustralia.org.au
  Information about supporting siblings. Includes chat rooms for children, teenage and adult siblings.
  Enter through task bar at bottom of screen.

• www.siblingsupport.org
  Don Meyer is the director of the Sibling Support Project and developed Sibshops, SibKids and SibNet in US.

Picture Books


**Books for Older Readers**


**Other Resources**

• your local Autism Association

• Siblings Australia – [www.siblingsaustralia.org.au](http://www.siblingsaustralia.org.au)

• Kids Helpline – Ph 1800 551 800

• SIBS (Sisters Individuals Brothers) [www.sibs.org.au](http://www.sibs.org.au)

• your local carer organisations
• your local Child and Adolescent Mental Health Service

• movies e.g. *The Black Balloon*

References


• [www.thearc.org/siblingsupport](http://www.thearc.org/siblingsupport)