

SIBLINGS AND THE AUTISM SPECTRUM

– HOW PARENTS CAN SUPPORT
THE SIBLING RELATIONSHIP



AUTISM FINLAND



In a family with children one or more of them may be on the autism spectrum. Managing the daily life of a child with special needs may be highly demanding for parents. Siblings may experience feelings of injustice, especially if the child on the autism spectrum needs a lot of support. All of your children are unique and amazing. It is important to acknowledge the good qualities in each of them and also emphasize them to their siblings.

The sibling relationship is one of the longest relationships in life. Maintaining the relationship requires guidance and support from the start. Parents should consider the needs of all siblings when maintaining the relationship. When the child is diagnosed with autism spectrum disorder (ASD), it often leads to many emotions in parents and siblings. They may experience confusion, frustration and even feelings of loss. Children may have to deal with these emotions before their coping mechanisms have fully developed. It is important to remember that all the emotions felt by family members are acceptable.

“My brother never lies!”

“The greatest things are probably his distinctive way of joking and his persevering attitude.”

PROVIDE INFORMATION ABOUT THE AUTISM SPECTRUM

• WHY THIS IS IMPORTANT?

It may be tough for parents to talk about the autism spectrum. Children ask a lot of “why” questions. Be prepared to discuss what the autism spectrum means. The characteristics of individuals on the spectrum are highly unique, which is why it is important for the sibling to know how they manifest in his/her brother or sister. Information alleviates any fears and guilt the child may be feeling.

• WHEN IS THE RIGHT TIME TO TALK ABOUT IT?

There is no perfect time to talk about the autism spectrum with the other children. However, you should usually start quite early and gradually provide more information. Take the child’s age and level of development into account in your conversations.

“ I got support and information mainly from my parents. I also looked up information on the internet and found it useful. I would have wanted more support from outside my family as well, for example from school’s social workers or other support persons.”

• HOW SHOULD I TALK ABOUT IT?

Children often want to know why a person behaves or acts a certain way. Try to explain the reasons and purposes behind the behaviour. For instance, if the sibling on the autism spectrum has a certain habit of stimming (for example claps their hands, rocks back and forth, repeats words), explain why they do it.

You can compare how the siblings behave in similar situations. When one gets excited and starts to chatter, the other may

express excitement by jumping up and down. Keep your explanations age-appropriate and link them to everyday situations.

Keep in mind that your children are constantly observing and interpreting what you do. If your children notice you showing compassion despite difficult situations, they will most likely follow your example.

The way you explain the behaviour of your autistic child as a parent will also affect how the siblings will talk about it with their friends and what they will say. If you find talking about ASD challenging, you can ask a professional for help.

“My mom has always kept us siblings updated and I’ve grown up in an environment where I felt I could always ask about anything on my mind.”

Reading tip: Autism: talking about a diagnosis.
Written by Rachel Pike.
Publisher:
National Autistic Society



FAMILY LIFE

• “NOT FAIR!”

Children are often well aware of who has received more or less of something in the family. Feelings of injustice may be stronger in families with a child on the autism spectrum. Their siblings may feel that certain special arrangements are unfair and unreasonable.

Listening to music, turning on the lights or inviting friends over may not be allowed because these things increase the stress level of the sibling with ASD. It may be hard for the other siblings to accept these demands, even if they understand the reasons behind them.

There may also be different household rules for different children, for example relating to screen time or chores. It is important to address any feelings of frustration whenever they emerge. You should also try to maintain a sense of fairness. Each child can be responsible for a chore.

It is important for children to hear often that they are just as important and loved as their sibling. You can, for example, explain what the therapy sessions of their autistic sibling involve and how the therapy is helping them. You can also say that the sessions may not be as nice and easy as they seem, they require hard work.

“ Following the routines strictly would sometimes make me absolutely furious: when I was young, I couldn’t understand for instance why the ceiling light could not be switched on or why I couldn’t listen to music.”

• DIVIDING ATTENTION AS A PARENT

The children may feel like one of the siblings is getting more attention than the others. This is also often the case, because the sibling with ASD may need intensive support. Remember that even small actions and acknowledgements are extremely important. If possible, spend one-on-one time with each of your children, even for a brief moment every day. This moment can be, for instance, you taking the child to their hobby, allowing you to catch up on things without interruptions.

“ I felt a lot of jealousy. It felt like I had to grow up on my own, because by sibling needed all the energy my parents had. There were not many one-on-one moments with my parents, because my sibling needed constant supervision.”

• THE ATTITUDES OF SIBLINGS VARY

Every child experiences their sibling with ASD differently. There are many factors for example gender and age difference that play a part in that experience.

Younger children often mimic the behaviour of older siblings. If an older sibling is on the autism spectrum, it may be challenging to explain why a certain behaviour is acceptable for them, but not for others.

As a parent, try to avoid making assumptions of how you think the siblings should behave together and feel about each other. While one of your children may be overwhelmingly attentive and caring, the other may not necessarily show any particular interest towards their sibling.

“ I felt all the things that siblings usually feel! Irritation, anger, love, fear, protectiveness, tiredness, looking out for my brother and myself.”



CHALLENGES

• MIXED EMOTIONS

Families go through different emotions. All feelings are acceptable for children, both the negative and the positive ones. Children can also experience mixed emotions.

Sometimes the other children in the family can feel embarrassed about the unusual behaviour outside home. They may also feel guilty of being embarrassed. Listen to and help your children to deal with all their emotions.

Brace yourself for fierce outbursts, such as “I hate my brother!” or “I wish I didn’t have a sister!” Also tell them that all siblings sometimes have a hard time getting along. Encourage the sibling to talk about their feelings. Teach them also to respect everyone. Every person is different, and everyone has strengths and good qualities.

A special sibling relationship often has some positive effects. Having a sibling on the autism spectrum can teach one patience and independence. The acceptance of diversity is likely to stay strong throughout life.

“ I felt mostly love towards my sibling, just like I felt towards my other sibling. But I’ve also felt shame and bitterness and a kind of “why me” feeling. And because of these negative feelings I’ve felt like I’m an absolutely horrible sibling and person, so I haven’t really wanted to talk to my parents about it. The other thing is that I haven’t wanted to “burden” my parents with my personal worries because they’ve had a tough, hard time even without my worries. Perhaps I’m suffering from similar emotional dams even now as an adult.”

• CHALLENGING BEHAVIOUR

The boundaries of integrity may become blurred in families with a member on the autism spectrum, if the sibling with ASD behaves in a challenging way. The other siblings may experience feelings of anger, confusion and fear if they see or experience violence in the family.

The other siblings may also ask why their sibling gets away with such behaviour. Explain the reasons for the behaviour

(for example pain, sensory overload, frustration). Tell the siblings that it is not easy for everyone to express themselves and say that the sibling with ASD feels bad about it.

It is important that you do not downplay the incidents and the experiences and feelings of your children. Also remember that safety is the first priority. Listen to the concerns your children have and tell them how you will try to resolve the situation. Nobody should feel unsafe in their home.

“ My sibling’s challenging behaviour at home has evoked feelings of sadness in me from when I was quite small. I’ve often thought about what my sibling is really feeling and if they’re trying to tell us something with their behaviour. Challenging behaviour in public has caused some shame and feelings of humiliation.”

• CONCERNS ABOUT THE FUTURE

As the children grow up, they will start to think about their future and their siblings’ future. When the time and their age is appropriate, include the siblings in making plans for the future.

If your child on the autism spectrum will need supported housing services, listen to the other siblings’ thoughts on the matter. As a parent, support your children’s feelings and decisions and be open-minded towards the future. This will make your children to feel secure in terms of the future, regardless of the decisions they make. Acknowledge and accept that the siblings may have different needs and desires to engage in the life of the sibling with ASD who is learning to live independently. You may also have to come to terms with the fact that their thoughts are inconsistent with your plans.

SIBLING RELATIONSHIP

• GROWING UP TOGETHER

Every sibling relationship is different. Sometimes autism makes it more difficult to build a positive sibling relationship. It may be challenging to cope with various interactive situations and unusual expressions of affection or find common interests.

The parents cannot force siblings to develop a better relationship, but they can help them connect and come up with things to do together. Would your children be interested, for example in geocaching or games played in different ways?

“The moments when we laughed together or acted out funny Moomin scenes were magical. All of his achievements in various things were also great moments, we rejoiced in them together.”

• TIME APART

It is important for siblings to also have some time for themselves, take a break from each other.

Being a sibling can sometimes feel overwhelming. Many children benefit from peer support. You can ask about peer support for example from an autism association in your region. Children can also process their emotions and situations on adaptation training courses with others who are in a similar life situation.

Kela adaptation training courses

<https://www.kela.fi/web/en/rehabilitation-and-adaptation-training-courses>

It is important to keep in mind that there are many good ways to approach situations and be a parent. If your everyday life works out for you, there is no need to compare it to others. There probably is no such thing as a problem-free childhood or life. Experiencing exceptional or challenging situations does not put your child's development at risk, as long as you try to find solutions to the situations together. Resolving challenging situations teaches the child important skills.

The parents should take care of themselves and each other. When the siblings see that their everyday life is secure, they have the courage to believe in the future. Do not hesitate to ask for help and create a network to support your family. This network also provides vital support for the siblings.

“ I love being the sibling of a special person and I feel like I've grown up to become exceptionally considerate as a person and, because of this, I have a good foundation for life. I don't feel I've missed out on anything, quite the opposite.”



INFORMATION ABOUT THE AUTISM SPECTRUM

Autism spectrum disorder (ASD) affects how a person interacts with others and how they sense and experience the world around them. Autism manifests differently in each individual on the autism spectrum, that is why we call it a spectrum. Some persons on the autism spectrum are able to live very independently, while others may need strong support throughout their lives.

ASD affects

- interaction
- communication
- sensitivity to stress
- sensory processes
- executive functions

Autism also involves strengths, such as a good eye for detail and the ability to focus on special interests as well as a good sense of justice.

www.autismiliitto.fi

