

FEATURE

SIBLING SUPPORT



Giving Voice to Brothers and Sisters of Amputees

By Max Warfield

In the family car, tired, hungry and bored siblings clash noisily in the back seat. From the living room, a young brother complains that he does not get as much attention and compares himself to a fifth wheel. A teen sister groans about having way too much responsibility, exclaiming that she's too young to be the glue that holds the family together.

At breakfast, parents fraught with family fighting and pressing schedules treat aggression as normal. Communication is tense and unproductive. Stress shortens fuses and each day is a powder keg. The family includes a child amputee, but what about his or her sibling(s)? What are their roles in this family dynamic? What about the impact on them?

When a child is born missing a limb or undergoes amputation due to an accident or medical cause the entire family is affected, including siblings. Having a brother or sister who is living with a disability can be challenging at times for children and teens.

Studies show that being a sibling of a youth with a disability can have both positive and negative effects. These effects are contingent on interrelated factors such as gender, culture, disability type, peer relationships, family size, family functioning and connectedness, and the emotional availability of parents. Even simple things, like consistent household routines, are

linked to positive outcomes.

While most siblings are well-adjusted, they may be subject to increased risk of negative externalizing and internalizing behaviours, like anxiety, depression, guilt, and lower social competence.

It has been consistently reported that sisters of children and youth with a disability are especially vulnerable to the emotional demands of the family. They also take on a more parental role compared to brothers, and account for a higher incidence of emotional problems among non-disabled siblings.

Guidance for siblings of youth with disabilities can be found in peer support groups which offer knowledge about their siblings' experience and work to cultivate an understanding of their own role in the family. Family sup-

port groups are reportedly the most effective type of program in helping siblings, particularly when used alongside peer support groups.

Ability Online has been hiding in plain sight for decades as a safe place for siblings of those with a disability to meet new friends who share similar struggles.

"Some siblings are put into a role of caregiver very early," tells Michelle McClure, Ability Online's executive director.



RESEARCH SAYS... “The majority of 12-15 year-old-siblings of youth with disabilities felt their responsibilities were too much.”

“It’s ‘take your brother with you!’” says McClure. “And then you might see jealousy or resentment surfacing in different ways. They can become angry with their amputee sibling because they get more attention from their parents; not necessarily ‘better’ attention – but with doctor’s appointments, surgeries, follow-ups and so on. With those priorities, brothers and sisters can feel left out.”

Ability Online has earned the rare claim: “We’ve been running an online support community for 32 years!” The organization provides an innovative model of support for vulnerable youth and young adults with disabilities. The goal: reducing social isolation and increasing inclusion. “Our supportive and safe online community fosters positive attitudes and builds self-esteem which contributes to emotional health and wellness,” explains McClure. She adds, “Ability Online has always

held a special interest for siblings; always included them.”

As a well-liked social outlet, some kids enjoy the platform so much they insist that their family wait to celebrate their birthday until their Ability Online friends can join in. McClure knows that making the sibling of someone with a disability feel included requires intent and effort from the parent. Keeping everyone healthy and happy is always the goal, but the sibling’s feelings can become lost by the equally overwhelmed parent.

“The sibling may act out,” McClure shares. “We have seen that over the years. But they are just needing to have their own identity and the ability to live their life their way. Looking after their sibling can be all-consuming.”

The answer? Well, not clear-cut but McClure emphasizes that it’s about respecting and encouraging differences. “It’s about family dynamics; some parents lean a lot

on a sibling in the caregiver role. Some have the wisdom to let kids be kids.”

There is an economic factor to this as well. Where there is a family that is well-situated to hire help to give balance, so is there a less well-off family that can’t afford the support. One can afford different therapies; another can not afford a community caregiver. The level of challenge also depends on the extent of the disability.

Without intervention and help, some families can head toward trouble as all involved feel overwhelmed. If a caregiver does not schedule some time for his or her own needs, it becomes unhealthy. Self-care is paramount – one cannot give to others if they do not take care of themselves first. Family members may seem lost at home or school. A child might begin to question what is fair and what is within their control, fueling more stress. A sibling that is



RESEARCH SAYS... “Siblings may also feel guilt about being ‘normal’ and others report feeling stressed when parents expect them to treat their sibling with a disability ‘normally’.”

struggling may exhibit signs, like decreased concentration, apathy, perfectionism, along with hints of feelings of guilt, anger, numbness, sadness and helplessness.

In addition to counseling, the peer-to-peer programs available, including McClure's Ability Online, are effective. McClure's program started out as an online community for kids with a disability, so they would be able to connect with each other and not be alone with their challenges. It expanded to include siblings, and also to support parents.

"Everybody needs support in that whole dynamic," she says. "Providing much needed support is really important, whether that is just a distraction from life so that you can laugh with people that get you, or it's a shoulder to cry on. Parents talking to parents, kids talking to kids, sharing experiences."

As McClure observes, "if parents say something is good for you, it can sound like nagging, but if a friend tells you — you are more inclined to listen. Even the siblings, they can talk about loving their sibling but not loving the situation at times, and not being afraid to say that out loud!"

For decades, kids meeting other kids in the same shoes has encouraged youngsters. Don Meyer, from the state of Washington, understands this. He has written many children's books to this end, including *The Sibling Slam Book*, and introduced "Sibshops" in the early 1980s. He felt there were no play-based support models available to siblings. Today, Sibshops meet all over the world, including Canada. The organization describes these meet-ups as "pedal-to-the-metal events where kids meet other siblings, talk about the good and not-so-good parts of having a "sib" with special needs, play some great games, learn



something about the services their brother or sister receives, and have fun.

Sibshops offer get-togethers in a safe environment of kids on parallel paths. Siblings can openly share their joys and challenges, and even brainstorm new ways to handle different situations. The kids talk, listen, and make new friends. Parents appreciate how the service is geared just for siblings, providing a nice balance for the family.

The charity NowWhat Support Services in Ancaster, Ont., offers SibShops. In Ottawa, Able2 offers a therapeutic Siblings Group for children and teens. "Our Sibling Group runs every week, divided into four age groups up to seventeen," tells Heather Lacey, executive director of Able2.

"The facilitators who run our Sibling Group have clinical backgrounds," says Lacey. "It has a

clinically therapeutic premise because it can be hard to be a sibling. Care usually takes up a lot of time. Many don't understand disability. Here, siblings talk with each other about what it's like for them. They talk about their feelings all the while being educated about disabilities. We want to reduce the stress in the family and help individuals build better relationships." NowWhat surveys show that over 80% of participants experience a difference, and come back year after year.

While the kids are playing and learning, the parents are commiserating, having coffee, sharing issues, problems and pet peeves while offering solutions learned from experience. "All families have good intentions, but some realize that goals can seem out of reach without professional help," says Lacey.

"A family without a disability is stressful enough," she says.

RESEARCH SAYS... "The typically developing sibling may experience 'disability by association' and negative experiences such as increased responsibility, less attention from parents, and feelings that their family is different."

RESEARCH SAYS...



“As adults, siblings of a sister or brother with a disability were found to have higher tolerance of people, more compassion towards others, an awareness of the impact of prejudice, and stronger bonds with their families.”

*Helpful Resources: www.youth.society.uvic.ca to access Siblings of Youth with Disability
www.siblingsupport.org (Sibshops).*

FAMILY TIES *Tips to Help Parents Address Issues Siblings Face*

Source: War Amps of Canada

- Be open with brothers and sisters about the amputation. Explain the amputation in simple terms appropriate for the age of the child.
- Young children have vivid imaginations and sometimes think they have done something to cause the amputation, fear the same thing may happen to them, or are simply worried about the sibling with the amputation. Provide plenty of reassurance early on that everything is okay and make sure they understand the amputation.
- Encourage siblings to share their concerns and ask questions. By being open with a brother or a sister, parents pass on their positive attitude towards living with an amputation.
- Sometimes, because of doctor appointments and prosthetic fittings, you spend more time with the child amputee. Set aside some “special time” alone with other siblings to share an activity they enjoy.
- Treat the child amputee and his/her siblings equally by dividing chores according to age and ability. Firstly, siblings will see that no favouritism or special allowances are being made towards the amputee child. Secondly, it gives the amputee child more confidence as they take on and accomplish tasks like their brothers and sisters.



“A disability is an extra layer of responsibility that can feel overwhelming. Many siblings feel left out and that they are not getting the level of attention they need while the focus is on someone else. They need an outlet.”

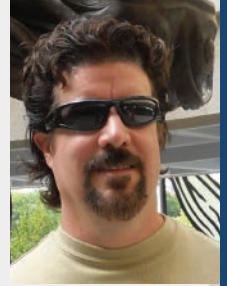
There are many family relationship skills that can be worked on to become proficient. “Good, productive communication — creating a family that opens up to each other while fielding questions are encouraged,” Lacey advises. “Being accepting of emotions rather than suppressing them is so important. So is being reassured how hard it is for parents to meet

everyone’s needs at the same time, and how to avoid favouritism.”

There are not a lot of sibling groups around. And youth face many mental health challenges. “The last couple of years has had such an impact on kids, leaving them questioning the uncertainty of school and their environment,” Lacey says. “However, I feel the pandemic opened a new door. Zoom has its faults but also its advantages. Meetings were easier to attend. Parents didn’t have to search for babysitters, and we had attendees from outside of Ottawa. Sibling support groups are ripe for enhancement and expansion.”

ABOUT THE AUTHOR:

Max Warfield was born in Ridgefield, Connecticut, now making his home on the southern shores of Lake Ontario.



A correspondent for the *Lockport Union Sun & Journal* and the *Niagara Gazette*, Warfield has also written and published several novels.



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