The Sibling Experience: What Parents Need to Know

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Why sibling issues matter to parents
When we, as parents, learn that our child has a disability we often respond by learning everything we can about the disability and actively advocating to ensure that our child’s needs are met.

Sometimes, we unintentionally overlook the needs of our other children.

If our child’s disability requires services or support into adulthood, we often are the ones responsible for ensuring that our disabled adult child is taken care of.

Sometimes, we need to pass that responsibility on to our other children and we don’t always know how to prepare ourselves – or our children – for this shift in roles.

Purpose of this call
The purpose of this call is to help you understand key sibling issues, understand how to foster a positive sibling experience, how to support young and adult siblings, and what resources are available to help you along the way.

Parents: helping yourself helps your child
Dealing with a child’s disability and managing the associated family dynamics is difficult to do alone. The more supported you are, the better able you are to support each of your children. We encourage you to

- Connect with other parents/caregivers of siblings who share common experiences.
- Get involved in the sibling support movement.

The young sibling experience
What is it like to grow up with a brother or sister who has a disability?

- The sibling experience is influenced by many factors, including the attitude of parents/caregivers and the type of disability.
- Siblings of children with disabilities/special health care needs have unusual opportunities for growth, and many of these siblings develop into compassionate, loyal and insightful individuals.
- Siblings of children with disabilities face daily challenges; parents and peers may overlook or misunderstand these.
- Siblings often grapple with difficult and conflicting emotions such as confusion, shame, worry, anger and resentment.
The Sibling Experience: What Parents Need to Know, Continued

How to support young siblings
When children are young, parents directly impact how a child responds to their brother/sister's disability. You can help your child
- acknowledge their complex family lives and their conflicting feelings early on.
- understand that they are not responsible for their brother/sister's disability; they didn’t cause it, not can they fix it.
- have the opportunity to express their feelings in a safe and nurturing - encourage them to participate in a sibling support group.

What happens as siblings get older
The shift from child to adult can be challenging in every family. For siblings of brothers/sisters with a disability, these can be especially complex times. As parents, we may have a vision of how we want to define their role in the family. Sometimes, that is at odds with what they want their role to be.

How to support your teen/adult child
Older siblings may need help and support in order to
- Balance their own lives & their role as a sibling.
- Navigate a world that often defines “family” as “parents” and leaves out siblings
- Seek opportunities to connect with other siblings informally or formally

Transitioning caregiver role to siblings
As you get older, you may find that you need to transfer caregiver roles to your children. At this stage, your adult children need help
- Learning how to navigate the system;
- Understanding legal and financial issues.
- Working together as a family to make a plan for future care

Overwhelmed yet?
- For parents who are focused on managing a son or daughter's disability, learning about sibling issues can seem daunting.
- Across the state and across the nation, people are working to ensure that siblings are supported across their lifespan.

Sibling Support movement
For the last 10+ years, adult siblings, researchers, policy makers, and service providers have been working to raise awareness of sibling-related issues.

As leaders in this movement, we are actively engaged in
- supporting siblings
- encouraging siblings to take on leadership roles in their communities and within the field of disabilities, and
- promoting family policy initiatives.
Since 2006, The Sibling Leadership Network has held an annual conference to discuss sibling-related issues, develop yearly action plans, and support family policy initiatives.

**Core values/beliefs of the SLN**

- We value family support in its fullest extent. This means that siblings need to be involved to the fullest extent they can be/wish to be.
- We believe that brothers and sisters have a unique understanding/perspective of the oppression of people with disabilities.
- We value self-determination of our brothers and sisters with disabilities and vow to support them in being as independent as possible.
- We believe in the “dignity of risk.” This means that we value providing our siblings with opportunities to try things out— even if it means failure— as long as they have the necessary supports to do so.

**MSSN: Supporting siblings in Massachusetts**

The goal of The Massachusetts Sibling Support Network (MSSN) is to support siblings of people with disabilities in Massachusetts. This support is offered across the sibling’s lifespan and includes providing information, creating welcoming communities for siblings, and improving access to sibling services.

**MSSN current programs**

- Meetups for adult siblings...building networks
- Adult sibling panel discussions
- Parent Advisory Committee (PAC) presentations
- Connected with local service organizations that have sibling support groups, such as the ARCs, etc.

**MSSN future programs**

To achieve our mission, we will

- Educate siblings about their role in the family and as caregiver
- Create communities for siblings that support them through their lifespan
- Improve access to existing sibling services
- Expand range of sibling services

**Resources**

Massachusetts Sibling Support Network  
info@masiblingssupport.org  
617 807 0558  
Our website and social media presence will be coming soon.

SibParent – a listserv just for parents can go to talk about their “other” kids.  
http://www.siblingsupport.org/connect/sibparent-a-listserv-just-for-parents
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Sibling Leadership Network
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www.siblingleadership.org
They are also on Facebook and Twitter