



Wrap Up Inside!

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What's Inside...

This issue of *Bridges* highlights
Siblings

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Luis, Aracely and Xavier Velazquez

Siblings of Children Who Have Disabilities

Excerpts from **Sibling Issues**,
Center for Parent Information and Resources

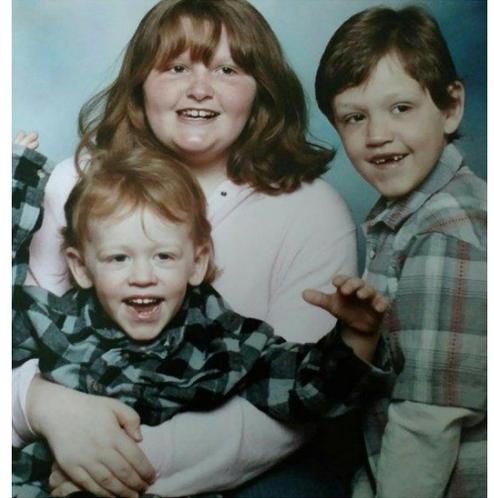
<http://www.parentcenterhub.org/repository/siblings/#self>

In any family, each sibling is unique, important, and special. So are the relationships they have with each other. Brothers and sisters influence each other and play important roles in each other's lives. Sibling relationships make up a child's first social network and are the basis for their interactions with people outside the family.

Brothers and sisters are playmates first; as they mature, they take on new roles with each other. Over the years, they may be many things to each other — teacher, friend, companion, follower, protector, enemy, competitor, confidant, role model. This relationship can be powerfully affected by a sibling's disability or chronic illness.

It's different for everyone

The impact of disability in the family varies considerably from person to person. For many, the experience is a positive, enriching one that teaches them to accept other people as they are. Some become deeply involved in helping parents care for the child with a disability. It is not uncommon for siblings to become ardent protectors and supporters of their brother or sister with



Kathleen, Billy, and Bobby Buick

special needs or to experience feelings of great joy in watching them achieve even the smallest gain in learning or development. Megan, age 17, says of her life with her brother who has Down syndrome:

Every day Andy teaches me to never give up. He knows he is different, but he doesn't focus on that. He doesn't give up, and every time I see him having a hard time, I make myself work that much harder...I don't know what I would do without Andy. He changed my life...If I had not grown up with him, I would have less understanding, patience, and compassion for people. He shows us that anyone can do anything.

In contrast, many siblings experience feelings of bitterness and resentment towards their parents or the brother or sister
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2017 Celebration Honors Community Champions

On Saturday, May 13, more than 200 guests gathered in the Grand Ballroom of the Holiday Inn Downtown to raise money to support Starbridge and celebrate the good work done by our 2017 Community Award recipients.

Several of the award winners spoke about the importance of collaboration and acknowledged others who supported them along the way. All of the speeches shared the themes of continued hope for change and a future in which every person is supported and included. Don Alhart of 13 WHAM-TV served as emcee, and we thank him for donating his time and talents in support of our event.

Tony Hiler and Watercolors Contemporary Jazz Band provided musical entertainment. The silent auction offered art from local artists, recreation, sports, and entertainment packages.

Thanks to the support of corporate and private sponsors, and event guests, our agency raised more than \$18,000. Funds raised this night will support Starbridge's programs to connect people with the hope and the how. Thank you to everyone who made this year's event a success!

To read more about the 2017 winners and their stories, please go to <http://www.starbridgeinc.org/news-events/news/212-2017-community-award-winners-announced>



[L-R]: Colin Garwood, Don Alhart, George Gray, Michael Doherty, Gaie Sarley Goodness, Lawana Jones, Sapna Ramesh, Karin Vay representing Wegmans, and Rick Wright

During the presentation, Starbridge launched its newest video to highlight the personal stories of people who have come to our agency for help with education, employment, and living independently. You can see the video "Sometimes Life Has Other Plans" here <http://www.starbridgeinc.org/news-events/video-stories>



Starbridge Workshops, Conferences & Special Events

Check our website event calendar for updates! www.starbridgeinc.org/events

Ask the Advocate

Allegany and Cattaraugus Counties

Do you have questions or concerns about your child's special education program?

An educational advocate will be available to speak individually with parents or family members to answer questions and offer ideas for you to address your concerns.

Join us at one of the locations listed below!

Registration is not required. **Pizza and beverages will be available at each location. Either a gas card or a grocery gift card will be available for each family that speaks with an advocate.**

Allegany County

June 13, 6:00-7:30pm

Cuba Circulating Library
Children's Room
39 E. Main St., Cuba, NY 14727

June 26, 6:00-7:00pm

Arc Family Support Group
Alfred State Campus
Pioneer Student Union
2540 River Rd, Wellsville, NY 14895

Cattaraugus County

June 15, 6:00-7:30pm

Randolph Free Library
26 Jamestown St.
Randolph, NY 14772

June 20, 12:30-1:30pm

Ellicottville Memorial Library
6499 Maples Rd.
Ellicottville, NY 14731

June 21, 6:30-7:30pm

Olean Public Library
134 North Second St.
Olean, NY 14760

Belonging Matters - The Keys to Relationships

Featured Speaker: Al Condeluci, PhD

August 17, 2017 | 8:00am-4:00pm



Having a network of meaningful relationships—called “social capital”—is a critical component of building a healthy, happy life for all people. Internationally respected scholar Dr. Al Condeluci will examine the importance of social capital for people who have disabilities, how friendships can be better developed, and how this leads to inclusive, vibrant communities.

Join us for the morning session, afternoon session, or full day conference!

Registration and breakfast—8:00-8:30am

(No food is allowed in The Strong Auditorium)

Morning session—8:30-11:30am

The first session will cover the realities of relationships and the impact of social capital in our lives. We will examine social capital and the impact of community engagement.

Afternoon session—1:00-4:00pm

The second session will focus on strategies of building social capital and ways to develop friendships. Al will engage us in exercises to help frame concepts.

Location: The Strong, One Manhattan Square, Rochester, NY 14607

Fee: \$99/person for full day; \$59/person for half-day session
Fee includes continental breakfast and afternoon snacks *(Limited number of scholarships available for people who have disabilities, or their family members. Call 585-224-7248 to apply.)*

Lunch is not included in the registration fee. The Strong offers a food court and restaurant on-site.

Parking: The Strong is a popular destination year-round. Registrants arriving for the afternoon session or leaving campus at lunchtime should plan to arrive early to find spaces.

Register & pay online at www.starbridgeinc.org/events

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Siblings of Children Who Have Disabilities

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with a disability. They may feel jealous, neglected, or rejected as they watch most of their parents' energy, attention, money, and psychological support flow to the child who has a disability. As Angela, age 8, puts it, "There are times when I sit down and think, 'It's not fair!'"

And many, many siblings swing back and forth between positive and negative emotions. Helen, age 10, whose sister has severe intellectual disabilities and seizures, begins by saying that she's glad to have a sister with special needs:

It has opened my eyes to a world of people I never would have known about.

But Helen also says, "Sometimes I wish I had special needs. I think that a lot when Martha gets oohed and aahed over and nobody even thinks about me."

Then in the next breath, Helen says, "Another thing is that it really makes me mad when kids slap their chest with their hands and go, 'I'm a retard!' It made me so mad!"



Ashlee, Adam and Justin Joachimiak

Age can make a difference

The reaction and adjustment of siblings to a brother or sister with a disability may also vary depending upon their ages and developmental levels. The younger the sibling without disabilities is, the more difficult it may be for them to understand the situation and to interpret events realistically. Younger children may be confused about the nature of the disability, including what caused it. They may feel that they themselves are to blame or may worry about "catching" the disability.

As siblings mature, their understanding of the disability matures as well, but new concerns may emerge. They may worry about the future of their brother or sister, about how their peers will react to their sibling, or about whether or not they themselves can pass the disability along to their own children.

Talking with your children about disability

Clearly, it is important for you to take time to talk openly about your child's disability with your other children, explaining it as best you can in terms that are appropriate to each child's developmental level.

Benefits of being the sibling of a child who has a disability include:

- Developing a level of **maturity** that is greater than their same age peers
- Increased frequency of **pro-social behaviors** (*helping others, empathy, etc.*)
- Deep **understanding** of challenges of others and the advantages most people take for granted
- Increased **tolerance** for diversity
- Feeling of **pride** about accomplishments of disabled sibling
- A deep sense of **loyalty** and **caring** towards sibling (*defending siblings*)

-Dilemmas and Advantages of Siblings of Special Needs Children, Kaiser Permanente, https://mydoctor.kaiserpermanente.org/ncal/Images/GEN_Sibling%20of%20your%20Special%20Needs%20Child_tcm63-13832.pdf



Jacob and Natalie Dixon

New Resource for Adult Siblings



*Interview with
Carol Blessing,
Project Director of
SiblingResources.org
and Principal
Investigator of*

*Citizen-Centered Leadership at
Cornell University.*

Have we as a community addressed the needs of siblings sufficiently?

Historically, service providers have not included adult siblings in planning for supports and services with and for their brothers and sisters. Typically it is the parents of people with disabilities that are involved in discussion and decision-making about their family member. Over the last decade, more attention has been paid to siblings of people with intellectual and developmental disabilities. This is due, in part, to the fact that people with IDD are living longer and may need their siblings to fill their need for support and advocacy that was once filled by parents.

Additionally, and equally important - maybe even more important - is that siblings tend to have the longest relationship to one another than anyone else in their lives. There is a shared history and a shared story. Because of this, adult siblings of people with IDD bring a perspective that no one else can bring. The sibling perspective is a peer, rather than a parental, perspective.

When adult siblings are not traditionally part of the planning discussions and decision-making processes that shape the supports that their brother or sister receives, it can be confusing and difficult to “get with the program” if they are called upon to step into an

advocacy role. Providers need to be aware of and sensitive to this when working with adult siblings for the first time. That is why SiblingResources.org devotes tips, training and resources to both the adult sibling and to the service provider.

One more point to make: Adult siblings of people with IDD are juggling their own lives and families, maybe in combination with supporting elderly parents, and taking on the added responsibility of advocating for their brother or sister can be overwhelming for some. Adult siblings need to know that there are other adult siblings - lots of others - out there that they can connect to in multiple ways. Access to local or regional sibling groups through formal and informal channels (i.e. meet-ups, workshops and conferences); connections through social media and other online networking resources are crucial. That is why SiblingResources.org is such a great and timely initiative.

Tell me about your new project.

SiblingResources.org is a new dynamic networking and information website for adult siblings of people with intellectual and developmental disabilities, (IDD).

Included within the site are resources dedicated to disability service professionals and other sibling supporters who are interested in understanding and expanding the important role that adult siblings play in the lives of their brothers and sisters.

SiblingResources.org is a blend of self-paced, live and archived web-based training opportunities; links to timely resources, including information about how to advocate within the service delivery system;

downloadable documents and tools; and; access to and membership in a growing statewide and national sibling network.

Launched in December of 2016, the website is being developed by the Lisa K. Yang and Hock E. Tan Institute on Employment and Disability in the ILR School at Cornell University. It has been made possible thanks to a two year grant funded by the New York State Developmental Disabilities Planning Council.

What is the mission of the project?

The mission of SiblingResources is simple: to connect adult siblings to one another in an expanding network throughout New York and beyond. SiblingResources.org provides at-your-fingertips relevant information to, for and about siblings of people with intellectual and developmental disabilities. Consequently, the website invites feedback and suggestions from visitors and members of the network to ensure that content reflects what is most important and needed by siblings and their supporters.

continued on next page





New Resource for Adult Siblings



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What is your role?

As project director, my role is to make sure that SiblingResources accomplishes its mission and meets the expectations of our constituency. One of the most important elements of my job is to work in collaboration with the national Sibling Leadership Network, (SLN) and the SLN New York Chapter, SibsNY to advance the active membership of the network throughout the state.

What do you hope to accomplish?

Right now, SibsNY is solidly established in the New York City and Long Island region. We intend to expand the network and the SibsNY presence within other regions.

Has anything surprised you in your research so far?

Listening to the stories that are shared about growing up with and becoming an adult sibling of people with IDD are incredibly powerful. While every experience is as unique as the person sharing it, there is a common thread that binds adult siblings together. There is a magic that is hard to describe.

The response to this project has been remarkable. New registrations to the network happened almost the minute the site opened and was announced. There is a real hunger for this work. People have joined from as far away as Canada.

What can siblings expect to gain from being involved in the project?

Our goal for this project is to offer information, opportunity and resources that support siblings and sibling supporters gain a sense of clarity and balance about personally relevant issues of advocacy and the many ways in which to navigate them. There is no “right” or “wrong” way to be a sibling.

Those who are interested in accessing SiblingResources.org to take advantage of its offerings may expect to

- Build understanding of the vital and important role of planning for the future throughout all of the life stages
- Build adult sibling confidence in navigating the service delivery system if and when they find that they are primary advocates with and for their brother or sister with an intellectual and/or developmental disability
- Build networks of relationships, find support and resources
- Understand the unique perspective of being a sibling of a person with IDD
- Recognize the importance of whole family planning earlier than later
- Stay informed about upcoming events and opportunities

Join SiblingResources on Facebook, Twitter and LinkedIn:
@SiblingResources | www.Siblingresources.org



Resources

What Siblings Would Like Parents and Service Providers to Know

www.siblingsupport.org/publications/what-siblings-would-like-parents-and-service-providers-to-know

Siblings of Children with Special Needs

http://www.aboutourkids.org/articles/siblings_children_special_needs

What About Me? — Support for the Siblings of Disabled Children

<http://psychcentral.com/lib/2006/what-about-me-support-for-the-siblings-of-disabled-children/>

Siblings of Kids with Special Needs

<http://www.med.umich.edu/yourchild/topics/specneed.htm>

When A Sibling Is Disabled

<http://psychcentral.com/lib/2007/when-a-sibling-is-disabled/>

Parenting Siblings of Children with Disabilities

<http://www.parents.com/parenting/better-parenting/teaching-tolerance/parenting-siblings-of-children-with-disabilities/>

Eight Things Siblings Struggle With

https://www.washingtonpost.com/news/parenting/wp/2016/12/20/8-things-siblings-of-children-with-special-needs-struggle-with/?utm_term=.9873c5762d80

What Siblings Would Like Parents and Service Providers to Know

<https://www.siblingsupport.org/documents-for-site/WhatSiblingsWouldLikeParentsandServiceProviderstoKnow.pdf/view>

How to Let Young Siblings Know You Care

We asked over fifty adult brothers and sisters: When you were younger, what did your parents, other family members, and service providers do to make you feel special and let you know they cared? This is what they told us.
<https://www.slideshare.net/DonMeyer18/how-to-let-young-siblings-know-you-care>

Ten Great Books if You Have a Sibling with Special Needs

<http://www.friendshipcircle.org/blog/2016/08/04/10-great-books-if-you-have-a-sibling-with-special-needs/>

Sibling support:

The Autism Council - <http://www.theautismcouncil.org/what-we-do/family-programs/>

Sibling Leadership Network - <http://siblingleadership.org/>

NYS chapter - <http://sibsnny.org/>

NYS Facebook page - <https://www.facebook.com/groups/330246825071/>

SiblingResources.org - www.SiblingResources.org

AUTISM SIBLINGS INITIATIVE

Downloadable colorful guide workbooks and booklets for parents, autism siblings, and self-advocates

OAR's (Organization for Autism Research) "Autism Sibling Support" initiative offers guidance for

young children, teenagers, and parents on how to productively address the ups and downs that may arise for individuals who have a brother or sister with autism. The resources below were written by siblings, for other siblings.

Young Siblings Guide: Autism, My Sibling, and Me

<https://researchautism.org/resources/autism-my-sibling-and-me/>

Teenage Siblings Guide: Life as an Autism Sibling: A Guide for Teens

<https://researchautism.org/resources/life-as-an-autism-sibling-a-guide-for-teens/>

Parent's Guide: Brothers, Sisters, and Autism: A Parent's Guide to Supporting Siblings

<https://researchautism.org/resources/brothers-sisters-and-autism-a-parents-guide/>

2017 Sibling Leadership Network National Conference, Hartford, Connecticut

June 24-25, 2017

Celebrating the Sibling Voice

An opportunity to connect with other adult siblings of people with disabilities and those who care about siblings. In partnership with AAIDD (American Association on Intellectual and Developmental Disabilities).

For further information, please see <http://siblingleadership.org/2017-sln-conference/>

Bridges

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From the Editor:



Dear Sibling,



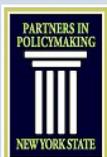
At times, you may experience anger, frustration, impatience, embarrassment, or sadness regarding your sibling who has a disability. It's OK. You are not alone. Your parents, family members, and friends may share some of your feelings; and siblings universally, regardless of ability, can identify with some of your difficulty.

It may be very helpful to share these feelings with a parent or relative, a close friend, other siblings, a counselor, or other professionals. They will help you realize that your reactions are normal and natural and suggest ways to work through your feelings in a healthy way and grow in understanding.

While you will share much of your life with your sibling, it is good and healthy for you to have a life apart from your sibling. You will pursue your own interests, develop friendships, and enjoy activities apart from your sibling. Your sibling will develop a life apart from you, too.

It may help to remember that your sibling who has a disability will at times have negative feelings toward you simply because you are human and will make mistakes. You may have more in common than you realize.

Maria Schaertel



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