



COMMUNITY CONNECTION

in partnership with



Spokane County
Parent Coalition



Glass Children

Tami Leitz

Spokane County Parent to Parent Coordinator

After finding my daughter crying in her room and comforting her, I asked what had made her so upset. She told me she had been in there for hours, and that I hadn't noticed because I was helping her sister who has Down syndrome and autism. She said, "I am invisible." No matter how hard she tries to have a good day, it doesn't matter because her sister will be mean regardless. Through her tears, she shared how she had been working so hard for so long to make things better, but no one noticed, and that sometimes she hated being Claire's sister.

To some, that may sound dramatic, but the reality is her life is not the same as others. I can't make our home less locked-down or promise that her teenage sister will stop stealing and breaking her things. We can't all go on a weekend outing without the possibility of an adult-sized person throwing a very public tantrum. I can listen and validate her feelings. I can continue to work towards the best-case scenario for everyone in the

family, but she knows the reality. My time and efforts will be disproportionately distributed to her sister and the issues related to her disabilities.

Most parents can relate to the dramatic, all-consuming change of identity status that comes with parenthood, but we can also remember when our lives were not centered around our child and can look forward to a time when their needs will be less demanding. This perspective gives us a leg up in our journey of growing into a healthy, whole person, connected but independent from our child. However, that process is much more difficult while raising a child with a high level of support needs. When every waking moment is easily swallowed up by caregiving, research, therapy, appointments with doctors and specialists, surgeries, monitoring medical equipment, advocacy, and behavior support, indefinitely our sense of self can quickly fade away. The demands of one person seemed to have compressed all of me into one identity: Claire's mom. Every time I received a call that she bit another child or pulled someone's hair, a wave of guilt would wash over me, as though I had been the one to hurt the students involved. It has taken years of therapy and introspection to make peace with my new identity, integrating who I was with who I am.

Now imagine never having a time when you were not impacted by the support needs, emotions, behavior challenges, and medical care of a person with disabilities in your home. You are tied to this person for the rest of your life. Even if your parents do not ask you to help manage your sibling's behavior, you feel compelled to because the fallout will affect your life. How might your perception of yourself and the world around you change?

The term used to describe siblings of people with support needs above and beyond normal parenting demands is "glass children," not because they are fragile, but because they are see-through. Their parents and the people around them often see right through them to the needs of their sibling with a disability. Glass children build their identity inside the context of their unique family structure, often hiding their own struggles for the sake of their family. Siblings do not take for granted things like their family being at their basketball game (that is way too overstimulating for their sibling). They are constantly and quietly adjusting and planning for the needs of their family while struggling to express their own feelings for fear of causing more stress.

Parents of people with disabilities carry an immense weight of responsibility for all their children's wellbeing. Their lives no longer keep pace with their peers, putting pressure on their work and personal lives. Getting through each day can be overwhelming and planning for the future feels daunting. Everyone in the family is adjusting but rarely are family members sharing their concerns with each other or openly discussing what life will look like when parents are no longer available to care for the family member with disabilities.

Glass children are often told by well-meaning adults, "You are so brave, strong, patient, compassionate." They say, "I could never handle that," causing glass children to feel further isolated. Being deemed a hero does not validate the real struggles they face and have had no choice but to endure. They work hard to make life better for their families and fit into a world that, all too often, does not accommodate their family's needs. But

building an identity around having no needs inevitably backfires. Brené Brown said, “The opposite of belonging is fitting in because fitting in is assessing a group of people and thinking ‘who do I need to be, what do I need to say, how do I need to act,’ and changing who you are. True belonging never asks us to change who we are. It demands we be who we are. If we fit in because of how we have changed ourselves that’s not belonging. You betray yourself and that is not sustainable.”

Belonging is being a part of something larger, but it is also the courage to stand by yourself. Glass children need to be encouraged and supported to take risks and pursue their own goals. They especially need to feel valued for who they are, and not just what they do for others.

Trying to protect glass children from difficult conversations does more harm than good in the long run. Parents feel sorry for passing on unresolvable challenges. We as parents feel guilty that we don’t have all the answers and may not be around to help navigate difficult systems and situations. But we must stop feeling sorry and start empowering ourselves and our kids. Glass children have consistently shared that they knew, without ever being told, that they would one day be responsible for the care of their adult sibling and wished their parents had been more upfront about the future. Glass children feel seen and experience less anxiety when their parents allow them to be a part of future planning and involve them in discussing what plans are already in place and what other options could be explored. Parents can talk to their kids about how they handle stress and model self-care. A team approach that includes all the children in future planning conversations can help those glass children feel seen and also empower the child with disabilities.

Siblings need opportunities to be around others who share similar experiences. You can find sibling support groups for all ages online. An organization called Sibshops trains volunteers and creates curriculum for sibling support groups across the country, including right here at The Arc of Spokane. Sibshops are high-energy, play-based groups that give children opportunities to talk about the good and not-so-good parts of being a sibling with people who get it.

Supporting a family can be as easy as spending some time with the child with disabilities so that parents and siblings can enjoy activities that would otherwise be stressful. Take a glass child on your family vacation, go to their band concert, invite them into your home. Just asking how they are feeling and then actively listening can be one of the most powerful things you can do for a sibling. Remember to validate their challenges without trying to fix or minimize them. They do not need to be reminded that their sibling has it harder than them or be reminded of all their parents are going through – they know. When you ask how they are doing or how you can help, they’ll probably say they don’t need anything or that they are fine. But remember, glass children struggle to express their own needs; they need a break.

Ask parents for suggestions or brainstorm what that glass children might like to do in advance: Would they like to do some back-to-school shopping? Play basketball at the gym? See a movie or get our nails done? We can

all help to build inclusive communities that support families, honor the independence and autonomy of people with disabilities, create opportunities for connection, and make glass children visible.

Additional Resources for siblings:

Sibshops: <https://www.arc-spokane.org/p2p>

[The SLN Podcast - Sibling Leadership Network](#)

[GROWING TOGETHER on Vimeo](#)

["Evelyn's Sister"](#) By Luna Diaz (children's book)

TYAP Pancake Breakfast

Whether you're already part of the program or interested in learning more, please join The Arc of Spokane's Transition and Young Adult Program for pancakes and holiday cheer! Current participants in TYAP can also bring along their friends or family.

The Pancake Breakfast will also host holiday-themed crafts, karaoke, and other activities!

There will also be a quiet space set up for those who may need to take a break.

WHEN: Saturday, December 10, 2022, from 10 a.m.-noon

COST: \$10 per person

WHERE:

The Arc of Spokane,
320 E. 2nd Ave,
Spokane, WA 99202

Register for the Pancake Breakfast [here](#).

Questions? Contact Kyla Parkins at kparkins@arc-spokane.org or [\(281\) 935-2160](tel:(281)935-2160).



That's My Story and I'm Sticking to it!

Taylor Crisp

Spokane Parent Coalition Self-Advocate

When I was in elementary school, we learned about the components of a story: characters, setting, plot, conflict, and resolution.

These components are needed when sharing your story in front of an audience, especially when sharing your own lived experience while testifying on federal and state legislative issues. Your representatives are the characters. The legislative district you reside in is the setting. The plot is the storytelling and your testimony. The conflict is the issue at hand, which in this case, would be the piece of legislation you're advocating for and how it affects you and your community. The desired outcome for the legislative piece you're advocating for would be the resolution. As a person who lives with IDD and is affected by various barriers in life every day, this how I can better understand this process, by breaking it down into these categories before sharing my story.

When sharing your story, highlight your key talking points (i.e., identifying the problem, sharing what's not working, offering a solution). Why does the issue matter to you? Are you trying to advocate for more funding for a specific program? How does this affect you, your family, and those in your community? What should Congress do to address it? Do lawmakers need to pass a new bill or update a current one? Ensuring your testimony answers these questions is a crucial part in effective legislative advocacy.

While including information about policies, laws, and data is important, your personal experience is what truly makes these policy implications much more impactful! Your story will show those in power that legislation is

more than just about numbers; it's about people and their quality of life. You never know whose mind (and heart) you can change!

Your story could be very influential if shared on various platforms: social media, rallies, newsletters, television, pictures, videos, postcards, presentations, community events, and even meetings with your representatives or legislators. From my experience as a self-advocate with IDD, I have had many opportunities to testify! What helps me feel most prepared is sticking to the script I've written beforehand, practicing ahead of time, and taking deep breaths to keep me from overthinking it. I remind myself why I am telling my story. It's okay to feel upset or to get emotional when sharing your lived experience and passion for change, but make sure to not let it distract you or your audience.

People don't remember statistics. They remember connection, tragedy, triumphs, heartbreak, and victory. Join me in creating legislative change for folks with intellectual and developmental disabilities and share your story!

Register for Fall into Fun activities

There's still time to sign up for Fall into Fun! Session themes range from crafting, karaoke and dancing, board games, and even a cooking class. Register for Fall into Fun events [here](#).

Upcoming Fall into Fun activities:

November 15: Fall Craft Night

November 22: Cooking Class

November 30: Board Game Night



Blaine Huizinga and his husband, Rhett

Introducing Blaine Huizinga

The Arc of Spokane's New Sexual Abuse Awareness and Response Trainer

The Arc of Spokane is thrilled to have Blaine Huizinga join the Advocacy and Family Support team!

Huizinga originally hails from Helena, Montana, and in 2011, he moved to Spokane with his then partner (and now husband), Rhett. With an extensive work background in customer service, he joined the team at a nonprofit organization in 2019 which provided crime victim advocacy for survivors of sexual assault and other crimes. He was then promoted to supervisor a year later. He expanded outreach and culturally relevant services to folks at higher risk of victimization during his time there. As an advocate for those with disabilities, he continued to promote awareness and better responsive service to the Spokane Community. Within his time, he became the local office's lead Diversity, Equity, and Inclusion (DEI) representative and continued to advocate for the needs of those across individual and intersecting identities spectrums. He also led a programmatic change to allow for further support of those across the LGBTQIA2S+ Spectrum.

When not working, Huizinga enjoys being able to travel and hike with his husband. They also enjoy watching Spanish art films and lounging with their rotund tabby cat, Chuy. He studied music in college and is looking forward to opportunities to share his musical training and talents in local performance groups.

Huizinga now comes to The Arc of Spokane with a passion to continue educating the community about awareness and response to those at greater risk of sexual harm. His knowledge and ability within the realms of impacts of sexual trauma, support for survivors and their support people to navigate their options, and healing and recovering from trauma have continued to help others. By working to restore justice, dignity, and quality

of life, the Advocacy and Family Support team has welcomed Huizinga whole-heartedly into their fold with their shared goals and values.

His work at The Arc of Spokane will focus on raising awareness of the realities and pervasiveness of sexual abuse within the IDD community, as well as educating parents, professionals, teachers, and first responders on supportive response techniques and how to be aware of the signs and report abuse. There are plenty of misconceptions and myths about why sexual abuse occurs as well as who is capable of harm. There is similarly a lot of misinformation about how to approach the situation when someone unfortunately is sexually assaulted and what options they may have to report, seek justice, and heal. Huizinga hopes to bring this awareness so that safety and knowledge to know what to do are easily accessible for all those connected to the IDD Community.

If your organization would like to receive training on this topic, please reach out to Blaine Huizinga at by calling bhuizinga@arc-spokane.org or (509) 789-8325.

Researchers: Majority of kids with ASD miss out on Early Intervention

All children with disabilities should have access to early intervention under federal law, but new research suggests that less than half of kids with autism are actually receiving such services. Read the complete article [here](#).

Why would anyone want to get involved with politics? Legislation is the reason why!

Katie Sutch

Spokane Parent Coalition Coordinator

Legislation is the vehicle that drives bills which, if passed, becomes law. Bills can be public or private. Public bills affect the general public whereas private bills affect individuals or organizations. When a bill passes both the House of Representatives and the Senate chambers and is signed by the president (if it's a federal bill) or governor (if it's a state bill) it become law.

It is legislation that guides everyday life. It governs our schools, hospitals, group homes, service providers and even non-profit agencies, like The Arc of Spokane. Legislation should be simple and straightforward laws that meet the needs of every citizen, but because we live in the 21st-century, nothing is simple.

Party lines are useful when talking about ideology, but they are not useful when talking about human beings. Cerebral palsy and autism do not care if you vote down a party line. Children do not care what party holds the chambers of government. Parents and children with IDD must navigate barriers, both physically while out in the world and systematic and social barriers that are harder to unpack. These barriers must be dismantled, and accessibility must be made for everyone. To do this requires heavy lifting. Who will stand up for your right to a free and appropriate education? Who will demand that DDA, and special education programs are fully funded? Who will push for competitive wages for direct support personnel and paraprofessionals? Who will fight for you and your family?

Your elected officials.

And you can help them by calling, emailing, texting, tweeting, and declaring your needs. Elected officials need to be educated about the unique needs of the IDD community because they are responsible for creating and passing legislation. Elected officials need to be held accountable, and if they do not fight for you then use your vote and voice to send a clear message [#IVOTEDD](#). There are 38 million disability votes in America, use them. Demand equity, inclusion, and accessibility. Accept nothing less. Get to know your legislators. ([find your representative](#))

The Advocacy and Family Support team is ready to help support IDD voters, allies, and self-advocates. The Arc of the US and The Arc of WA make getting involved easy. Sign up for action alerts at the [Action Center \(p2a.co\)](#). Attend Advocacy Days [Advocacy Days - Washington State \(arcwa.org\)](#). Tell your story. Reach out and contact the Spokane County Parent Coalition, and we can help you be involved in the 2023 legislative process. Together we can enact real lasting change.

For more information about the Parent Coalition and how you can get involved, contact Katie Sutch at ksutch@arc-spokane.wa or (509) 789-8797.

Supreme Court to weigh in on Special Ed disputes

The U.S. Supreme Court will soon hear arguments in a case centering on how families and schools go about resolving disputes over services for students with disabilities.

The justices said this month that they will take up the matter known as Perez v. Sturgis Public Schools, which raises questions under the Individuals with Disabilities Education Act. The high court will consider whether families that have settled IDEA claims can pursue lawsuits under the Americans with Disabilities Act without fully exhausting all administrative proceedings under IDEA. Read the full article [here](#).

SSI, Social Security benefits will see biggest rise in more than 40 years

Monthly payments to people with disabilities receiving Supplemental Security Income and other Social Security benefits will increase next year by the highest amount since 1981. Read the full story [here](#).

The Arc's Virtual Program Library continues to grow!

The Arc of the United State's Virtual Program Library is a robust and valuable resource for people with intellectual and developmental disabilities. Find on-demand activities and activities that service providers can facilitate for people and families to do at home. Service providers can also find and share resources that they can use to facilitate or deliver live, remote programming for people with IDD.

If you haven't stopped by in a while, visit the Virtual Program Library to access new resources [here](#).

Support The Arc on #GivingTuesday

#GivingTuesday is nearly here! The annual day of giving takes place on November 29, 2022 and if you're able to make a gift to help power The Arc, know that you're helping advocate for everyone to live a more fulfilled live.

Building an inclusive community is the cornerstone of The Arc of Spokane's mission, and brick by brick, that mission is helped by you and other friends of The Arc.

No matter how you choose to connect with and support The Arc, your efforts help expand our programming and empower others in the process.

Make your gift today: www.arc-spokane.org/give

Is your community boosted and ready?

Prepare for the cooler months ahead—and help keep those around you safe—by bolstering your immune defenses before a potential surge in COVID-19 cases this fall and winter. COVID vaccines and eligible boosters can prevent serious illness, hospitalization, and death from COVID, including from Omicron variants and subvariants. It is safe and recommended to pair the updated booster with the flu shot. Learn more and schedule your updated COVID-19 booster at [Vaccines.gov](https://www.vaccines.gov).

Learn More About [Parent to Parent](#) Resources

Parents may have questions and concerns as they learn about services that can help their child and family and often need time and support to navigate their own emotions and adjust to raising a child with special needs.

Personal support from fellow parent can help with:

- Emotional support for parents
- Information and referrals to community resources
- Connecting you to Trained Helping Parents
- Social and recreational events
- Current information on disabilities, medical conditions and community resources
- Training for parents who would like to become Volunteer Helping Parents
- Public awareness and outreach to the community regarding individuals with disabilities

Learn more about Parent to Parent resources [here](#).

Resource Spotlight through The Arc

Did you know The Arc of Spokane has a digital resource guide? Click [here](#) for information on a variety of different resources!

If you want a more comprehensive and personalized list of resources for your specific situation, please contact our Individual Advocacy Team at advocacy@arc-spokane.org or call (509) 789-8327. They will help you untangle complex issues and the service is free. The Individual Advocacy team is ready to help!

Contact Us

Contact the Advocacy and Family Support Team by emailing us at advocacy@arc-spokane.org.

Subscribe

Donate

The Arc of Spokane

The Arc of Spokane

320 E. 2nd Ave. | Spokane, Washington 99202

(509) 328-6326 | info@arc-spokane.org

Follow Us



Having trouble viewing this email? [View it in your web browser](#)

[Unsubscribe](#) or [Manage Your Preferences](#)

- This email and any files transmitted with it are confidential and intended solely for the use of the individual or entity to whom they are addressed. If you have received this email in error, please notify the sender immediately. Please note that any views or opinions presented in this email are solely those of the author and do not necessarily represent those of The Arc of Spokane. Finally, the recipient should check this email and any attachments for the presence of viruses. The Arc of Spokane accepts no liability for any damage caused by any virus transmitted by this email.

EXTERNAL SENDER