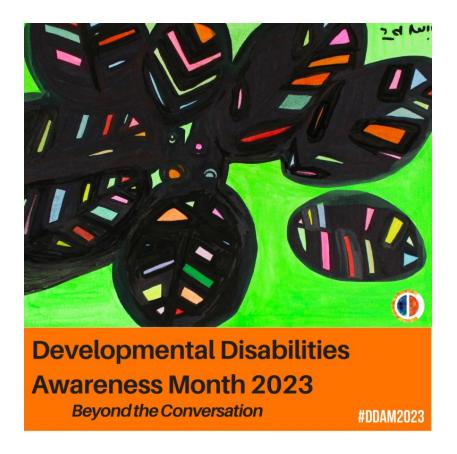


# DEVELOPMENTAL DISABILITIES AWARENESS MONTH

SPECIAL EDITION



# **Celebrate Developmental Disability Awareness Month!**

Each year during March, The Arc of Spokane joins in a nationwide celebration of <u>Developmental Disabilities</u> <u>Awareness Month</u>.

Stories are shared about our community members, trainings and workshops are held to promote advocacy, and The Arc engages with the greater Spokane community to put out the word about what it means to include people with disabilities.

The people we serve are the heart of the reason why we raise our voices during DD Awareness Month and more than six million Americans have developmental disabilities. Each one of those individuals deserves the right and support to live full, independent, and happy lives.

This annual campaign seeks to raise awareness about including people with developmental disabilities in all facets of community life. The month of March is set aside to provide opportunities to learn, educate, and draw attention to difficulties that people with disabilities still face today, and the ways you can partner with organizations like The Arc to make a difference.

Learn more about DD Awareness Month and view upcoming events and helpful resources here!

This year's featured artist for Developmental Disabilities Awareness Month is **Jamila Rahimi**.

Rahimi's work was selected from the DC studio <u>Art Enables</u> to serve as logo imagery for DD Awareness Month.

# **But Who Takes Care of the Caregiver?**

# Megan Juneau Advocacy and Family Support Program Manager

As someone who is fully immersed in the world of disability, I'm all too familiar with the loneliness and isolation that comes with being a caregiver. I've repeatedly witnessed and personally experienced the gaps in service, the detriment of being in a caregiving crisis, and lacking services and supports to keep going for just one more day.

I am both a full-time disability advocate at The Arc of Spokane as well as a full-time caregiver for **my father.** I spend more than 80 hours per week caring for and advocating on behalf of people with disabilities. I wear many hats as a direct support professional: daughter, advocate, social worker, friend, therapist, family member. But it's really hard work. It's difficult to listen to the painful experiences day in and day out. It's difficult constantly having to offer emotional support, resources, and solutions to clients, and then leave work to do those same things (and more) for a parent. Scheduling appointments. Housekeeping. Errands. Shopping. Personal hygiene.

But I move forward because it is my passion, purpose, and duty to work on behalf of and alongside people with disabilities.

My father has a rare form of neuropathy called multifocal acquired demyelinating sensory and motor neuropathy (MADSAM), in conjunction with multifocal motor neuropathy (MMN). His doctors aren't sure they've ever seen a patient with both diagnoses concurring. MADSAM is often misdiagnosed for ALS (amyotrophic lateral sclerosis, or Lou Gehrig's disease), as it results in the progressive loss of motor neuros that control muscles. MADSAM also involves stiff muscles, muscle twitches, and gradual increasing weakness and muscle wasting. His conditions are characterized by motor and sensory loss, paralysis of the muscles, extensive nerve damage, limb deformity, and muscle contractures. He was diagnosed with MADSAM more than 13 years ago and was told that if he lives long enough, he will eventually be paralyzed from his shoulders down. There is no known cause or cure.

All I've ever wanted for him is to continue to have autonomy over his life, to stay in his home for as long as possible, for him to have voice and choice, and to remain in the driver's seat of his life. But these diseases that

have robbed my dad in many aspects have been nothing short of overwhelming, confusing, and unpredictable for the both of us. They have brought feelings of hopelessness, insecurity, and doom. He has been through millions of dollars' worth of treatments (i.e. chemotherapy, weekly infusions, steroid treatments), none of which has stopped or even slowed down the progression of the diseases.

Both paid and unpaid, I have been the sole caregiver and financial provider of my father for more than five years. I do not have siblings to share the responsibilities, I do not have respite, I don't know anyone on my dad's side of the family; I have been carrying the burden of his wellbeing and quality of life by myself. And as his neuropathy has progressed over the years, my responsibilities in caring for him have progressed as well.

In December 2022, my father fell ill and his health began to rapidly decline. Within two weeks, he went from being able to spend the days while I was at The Arc moseying around the house, watching TV, doing light housework, showering independently, making a bowl of cereal each morning, to being entirely wheelchair bound and unable to put any weight on his legs, use his arms, and essentially experiencing quadriplegia. I realized we were in big trouble one day when he fell in the living room and I spent 20 minutes picking up and dropping 200 pounds of his weight repeatedly, plummeting into a total panic knowing I wasn't able to get him off the floor by myself.

I tried to get through this health crisis without asking for much help. I began staying at his house for 18+ hours at a time, on rotating shifts with my mom (his ex-wife) so he had 24/7 care. My mother and I took turns sleeping on his living room floor. I was transferring him by myself 20+ times a day, setting up appointments with his case managers, taking him to multiple doctors trying to get answers, looking for affordable medical equipment (shower chairs, transfer benches, wheelchairs, grab bars, toilet seat extenders, etc.), posting ads looking for additional help, all on top of my regular caregiving duties like housekeeping, meal preparation, and grocery shopping. I had missed more than two weeks of work at The Arc and wasn't sure what was going to happen to my career. There was no end in sight.

At one point, I reached out to The Arc's Director of Thrift Store Operations, Rose Williamson, to see if the Thrift Store had received any medical equipment donations that I could borrow or buy at a discounted rate. Rose quickly sent me a picture of what they had (a walker, a wheelchair, and two shower chairs) and told me to come pick up whatever I wanted. Two generous staff members, Jenny Eaton and Heidi Franks, listened to my story, helped me to identify and load up the equipment, and even consoled me as I fell apart in front of them.

A few days later, I posted on the Facebook group Spokane Quaranteam, asking if someone would be willing to plow my driveway. I had been spending 18+ hours taking care of my dad as he went through a medical crisis, and it had been impossible to keep up with shoveling. Our Executive Director, Sima Thorpe, and our Manager of Representative Payee Services, Tracie Thompson, both saw my request on Facebook and offered to help.

Sima called me at 7:30 that morning and offered to have our Facilities Manager, Duane Morrison come out with the company truck to plow my driveway. She told me that I should have been leaning on my family at The Arc and that I need to let people help me. Duane cleared my driveway within an hour of the call.

Director of Advocacy and Family Support, Jennifer Ranney, delivered hundreds of dollars' worth of premade meals to my family so that we could stop worrying about how we were going to eat. My Advocacy and Family Support team held down the fort, taking on additional responsibilities and serving my program's participants while I was out. Countless colleagues checked in, prayed for us, and cried with us.

My dad was admitted to the hospital in late December, where he stayed for 17 days as he underwent plasmapheresis treatment. This was our last hope in my dad ever walking again. He made a miraculous recovery and by the time he was discharged, he was crushing his OT/PT goals and walking up and down the hallway (backwards and sideways) multiple times per day. Since this emergency in December, my dad has safely returned to his home. It was a really special full-circle experience to return the donated medical equipment back to the Thrift Store for the next person in need.

I've been reminded that there are different kinds of help, that there are people that want to make things just a little bit easier for me, and people who deeply respect the love and dedication I put into the work I do for those with disabilities. Maybe members of your support system can't take over your personal hygiene, bathing, or medication management duties. But they *can* drop off a meal, shovel your sidewalk, or run an errand for the person you care for. It's usually asking for help that is the hardest part.

And while I am so grateful for his recovery, I know the fight is not over. It's just a matter of time before things begin sliding downhill again. Our situation has not changed and I am still looking for additional caregivers. I still need respite. It's still isolating and lonely being a caregiver. And the caregiving shortage is still very real.

With that shortage in mind, I ask that you join me in advocating to end the direct care workforce crisis.

Thousands of workers are unable to earn a living wage, and people with disabilities, as well as older adults, are struggling to find the care they need. And if they do have a caregiver, it is likely that the caregiver is burned out, lacking resources, and without respite.

According to The Arc of the U.S., "With an average annual turnover rate of 45 percent, an average wage of \$10.72 an hour, and an average vacancy rate of 9 percent, the needs of people with disabilities, their families, and the workers themselves are not being met."

An alarming article published by The Journal of Business on February 17, 2023, read, "Industry coalition WA Safe + Healthy has released new results of a poll in which 49% of health care workers in Washington say they are likely to leave the profession in the next few years. 68% of respondents said lack of adequate staffing was

one of their primary reasons for leaving, 79% reported being burned out, and 45% said they didn't feel safe at their health care job."

#### Show your support for HB 1694

This House Bill currently on the floor proposes the following:

- Directs the Department of Social and Health Services to design a pilot project to pay parents of persons with complex medical needs for providing care and to study the feasibility and cost of paying the parents of medically complex children under 18 years old.
- Expands the list of family members who are exempt from having to become home care aides and reduces the training requirements for these caregivers.
- Directs the Department of Health to establish a database to track and understand long-term care workforce data trends.

Consider sharing your story by submitting written or oral testimony to your legislators about your experience during the caregiver shortage <u>here</u>.

Join us for Advocacy Day on March 29 where we will address the workforce shortage here.

Sign the #CareCan'tWait Petition <u>here</u>.

# Sensory Story Time offered on Saturdays!

In partnership with the Spokane County Library District, The Arc has started up a Sensory Story Time at the Cheney Library! The story time is designed for those who need extra sensory support including children, adults, and their families, and caregivers. It will focus on interactive storytelling with sensory exploration such as music, art, and movement. Afterward, families will be able to participate in a sensory-friendly family playtime with other families.

From Parent to Parent Coordinator Tami Leitz:

"We were thrilled to welcome eight families who joined us for the first session. It can be hard to find things an entire family can do together, and we are excited to offer this opportunity."

Join The Arc and the Cheney Library each Saturday morning in March from 10-11 a.m., at 610 First St. Cheney, WA 99004.

# **Arc@School curriculum scholarships**

The Arc of Spokane's Parent to Parent is offering scholarships to the Arc@School in order to help family members of people with IDD learn the intricacies of navigating the education system. Register for your scholarship <u>here</u>.

# Let The Arc Egg Your Yard!

Support The Arc's transition programs and provide your children with a worry-free and effortless egg hunt on Easter morning! Reserve your Egg My Yard order <u>here</u>.

# Adulting 101

Learn about how to prepare for the workforce with Adulting 101. This course will cover resume writing, interview prep and practice, and more! Register for the April Adulting 101 series <u>here</u>.

# The Portal to Yes!

# Taylor Crisp Spokane Parent Coalition Self-Advocate

Have you ever felt you were trapped in a deep hole, so close to the top yet so far away? Being a person with a disability and a self-advocate, I am sure I am not the only one who experiences these feelings. But one day, I hope to enter a portal to a new world where those with disabilities experience the same opportunities for success as those without. Where we don't have a plethora of barriers in our way on a day-to-day basis. When will that door to a new world open?

I started my advocacy journey a little over a year ago and have grown so much as a self-advocate since then, though sometimes my impatience for change gets the best of me. Seeing all the laws and bills on the table holding the possibilities of change makes me want them all to pass and go into effect right now. However,

although everything hasn't been fixed yet, I feel just a little closer to success every day when I see different pieces of the puzzle start to fall into place.

I see myself on this advocacy journey and where it's taking me. I used to sit back on the sidelines where I would watch others conquer. Even though I knew I was destined for more, I felt stuck in place. I always longed and hoped for an even better future, especially as my 30s were approaching Although I often still question who I am and what I will become, I know we all struggle, whether we have a disability or not. However, I feel like I must try harder than others to jump over the hurdles and it is exhausting.

I am still learning how to advocate for myself. In my experience, whenever I would ask for help with a certain task or to reach a goal that really mattered to me, I would often get told "No." It's a word I've heard a lot in my life, especially during my childhood. I would be told that what I wanted was not possible or realistic. As a result, it shut me down to the point that I would stop asking for help and ended up doing things on my own, even when I really needed the extra assistance. But what would have really helped was to hear someone say "Yes."

In the systems people with disabilities have to exist within, we hear a handful of both "Yes" and "No" when it comes to change. I am ready to stand up to those who tell me "No." I will find a solution for myself and others. I want to knock those barriers down and say I will not take "No" for an answer!

My passion has grown now more than ever and I feel this fire burning inside of me. I will continue to fight no matter how long it takes until individuals with IDD have complete freedom. Everyone deserves the freedom to live and work in their own communities, have livable wages, be able to enjoy life outside of poverty, raise families, and most importantly, become leaders and lawmakers. Together we can conquer! I am excited to see these next chapters unfold and I can't wait to see this portal of success finally open.

### **Advocacy Days**

Advocacy Days are held each year to provide opportunities for individuals with intellectual and developmental disabilities (IDD), their families, and their service providers to make their voices heard by their legislators and to have an impact on policy and budget legislation that affects the services and supports available to them.

Sessions take place on Wednesdays and run through April.

Watch past sessions, learn more about legislative actions, and register for upcoming sessions here.

## **Fight the Algorithm**

# Jen Ranney Advocacy & Family Support Director

While on a walk the other day, I was listening to a playlist I had created on Spotify. At the end of the playlist, a song I had never heard before started playing. It wasn't a bad song, but I didn't love it. I forwarded to the next song, which I liked, but I found that I didn't care for the next song after that at all. I stopped to look at the "Recommended Songs" in the app which was based on an algorithm interpreted from my other likes, and I was genuinely surprised at the song recommendations. On several of the choices I thought to myself, "How in the heck did Spotify decide I would like THAT song?"

We have all seen algorithms in action. They are tools that predicts our behavior and as human beings, we are notorious for trying to predict the future. Marketing firms use it on a daily basis to try and automate our decision-making process for us (if you've looked at an ad on Google, you will get more ads based on what they *think* you "like"). They don't ask, they merely guess, and sometimes they are very wrong.

While thinking about the realm of disability advocacy, I couldn't help but make a correlation between algorithms choosing things for us to see, hear, and buy, based on what it *thinks* we want, and legislation that affects people with IDD and their families based on what people without a disability believe those with a disability need or want.

The Nothing About Us Without Us movement has anchored the work of disability rights advocates and demands the full and equal inclusion of persons with disabilities. More than 15 percent of the world's population remains largely excluded and underrepresented in legislation and politics. Stigma and stereotypes, especially the lingering belief that persons with disabilities are incapable of contributing to society, present significant barriers to persons with disabilities exercising their rights and participating politically.

Because of this stereotype, some people believe they must choose what is needed for people with IDD. They have created their own algorithm that assumes people with disabilities are perpetual children who must be protected from their own choices; that they are not capable of making empowered, educated decisions about their lives; or even want to make decisions about their own lives. This disenfranchises an entire population of people.

Allowing algorithms to make decisions for us, while easy, can perpetuate bias and undermine our creativity, choices, and opportunities.

This March during Developmental Disabilities Awareness Month, join The Arc of Spokane in telling our legislators that people with disabilities demand to have voice and choice in deciding what types of services and supports they need, and to not have them predetermined for them. They are the experts of our own lives.

If you want support or help in having your voice heard, contact Advocacy and Family Support at <a href="mailto:advocacy@arc-spokane.org">advocacy@arc-spokane.org</a>.

# **Inclusions and Literacy**

# *Tami Leitz Spokane County Parent to Parent Coordinator*

Inclusion requires intentionally. It is not enough to say, "They could come if they wanted to," without acknowledging that very real systems in place have separated people with disabilities from their communities.

Equality is not that everyone gets the same thing. True equity offers access to each person according to their needs. Unfortunately, it is rare to see this play out fairly in our lives. At all ages, people with support needs are separated from their peers. This segregation denies people with disabilities access to their communities and normalizes othering and isolation. Because this way of operating is so pervasive most people grow up without experiencing a meaningful relationship with someone who has a developmental disability. This is a disservice to everyone.

Without exposure to differences, people are inclined to become afraid of what they do not understand. It's easy to fall into the trap of moralizing behavior we are not familiar with and labeling people with disabilities as bad and deserving of separation from others.

Families of children with disabilities experience the loss of things most families take for granted. Sometimes it's a direct rejection; their child may not participate in a field trip or after school activities. Social rejection can be more subtle, like not being invited to playdates or birthday parties. The experiences pile up and repeatedly send the message that these families are not welcome. It can be challenging logistically to get out into the community when considering things like mobility, sensory input, and medical support. This quickly leads to isolation for families. Getting "out there" often requires being personally invited and assured there will be support.

Spokane County Libraries has partnered with The Arc of Spokane's Parent to Parent program to offer a Sensory Storytime, providing more opportunities for families to be intentionally welcomed into the community. Sensory Storytime will be held at the Cheney Library on Saturday mornings through March 25 from 10-11 a.m. This program is open to people of all ages to come experience the joy of stories, music, play time and crafts, designed to be as inclusive and adaptive as possible.

Creating spaces that challenge our learned preference for people who look and act the same as us is a worthy goal. One low-effort way to learn about disability is through self-aware and inclusive literature.

Think about the characters with disabilities or physical disfigurements you have seen in media throughout your life. Were they presented as a fully realized and complex person? Most likely they were the villain or posed a challenge for the protagonist to overcome. We also see people with disabilities portrayed as inspirational for simply living their lives, which is also othering to the disability community.

Here are some books recommendations that can challenge our misconceptions about disability and teach us to grow more inclusive communities:

#### Adults (Highly Recommend):

- Disability Visibility by Alice Wong
- Black Disability Politics by Sami Schalk
- Care Work: Dreaming Disability Justice by Leah Lakshmi Piepzna-Samarasinha
- Being Human by Judith Heumann
- Demystifying Disability: What to Know, What to Say, and How to Be an Ally by Emily Ladau
- My Body is Not a Prayer Request: Disability Justice in the Church by Amy Kenny
- Read This to Get Smarter About Race, Class, Gender, Disability and More by Blair Imani
- A Disability History of The United States by Kim E Nielsen
- Like Me: A Story about Disability and Discovering God's Image in Every Person by Laura Wifler
- Disfigured: On Fairy Tales, Disability, and Making Space by Amanda Leduc
- Beasts of Burden: Animals and Disability Liberation by Sunaura Taylor
- Exiles and Pride: Disability, Queerness and Liberation by Eli Clare
- Crip Kinship: The Disability Justice and Art Activism of Sins Invalid by Shayda Kafai
- A Quick and Easy Guide to Sex and Disability by A. Andrews
- Capitalism & Disability by Marta Russell
- All our Families: Disability Lineage and the Future of Kinship by Jennifer Natalya Fink
- The Ultimate Guide to Sex and Disability, Chronic Pain and Illness by Cory Silverberg
- Fighting for Yes!: The Story of Disability Rights Activist Judith Heumann by Maryann Cocca-Leffler
- Disability Pride: Dispatches from a Post-ADA World by Ben Mattlin

#### Youth (Disability Representation):

• A List of Cages by Robin Roe

- Pete Lyre's Rating Normal by Anna Whateley
- Marcelo in the Real World by Francisco X. Stork
- Queen of Geek by Jen Wilde
- On the Edge of Gone by Corinne Duyvis
- The Boy Who Steals Houses by C.G. Drew
- You, Me, and Our Heartstrings by Melissa See
- Wild and Crooked by Leah Thomas
- Wonder by R.J. Palacio
- A Taxonomy of Love by Rachael Allen

#### Children:

- We Move Together by Anne McGuire and Kelly Fritsch
- All Are Welcome by Alexandre Penfold and Suzanne Kaufman
- Why Are You Looking at Me? I Just Have Down Syndrome by Lisa Tompkins
- Brave by Stacy McAnulty and Joanne Lew-Vriethoff
- Strictly No Elephants by Lisa Mantchev and Taeeun Yoo
- Real Friends by Shannon Hale and Leuyen Pham
- It's OK to be Different: A Children's Picture Book by Sharon Purtill and Saha Sujata
- Just Right for You by Melanie Heyworth and Celeste Josephine
- All the Way to the Top: How One Girl's Fight for Americans with Disabilities Changed Everything by Annette Bay Pimentel
- The Black Book of Colors by Menena Cottin and Rosana Faria
- Fish in a Tree by Lynda Mullaly Hunt
- Just Like ME by Louse Gooding
- The Reason I Jump by Naoki Higashida
- Forget Me Not by Ellie Terry
- *I Will Dance* by Nancy Bo Flood and Julianna Swaney
- A Friend for Henry by Jenn Bailey and Mika Song
- Steggie's Stutter by Jack Hughes
- How I Learn: A Kid's Guide to Learning Disabilities by Brenda Miles and Colleen Patterson
- Be Good to Eddie Lee by Virginia Fleming
- *Hello Goodbye Dog* by Maria Gianferrari and Patrice Barton
- The Prince Who Was Just Himself by Silke Schnee and Heike Sistig
- We're All Wonders by R. J. Palacio

- *Not So Different: What You Really Want to Ask about Having a Disability* by Shane Burcaw and Matt Carr
- Who Do You See When You Look at Me? by Angela Ray Rodgers
- The Boy with Big, Big Feelings by Britney Winn Lee and Jacob Souva
- This Beach is Loud! by Samantha Cotterill
- My Three Best Friends and Me, Zulay by Courtney Butorac and Emily Ziaroth
- When Charley met Emma by Amy Webb and Merrilee Liddiard
- Welcome to the Autistic Community by Autistic Self-Advocacy Network

# **Journey to Advocacy**

# Stephanie Sherman-Petersen Individual Advocacy Coordinator

When I first shared the news with friends and family about my new career at The Arc of Spokane, the response I always got was, "Cool! So, what exactly will you do?" I had to admit that it was going to take some time for me to learn exactly how to define just what the Individual Advocacy program is, what it looks like, and why I knew I wanted to be a part of it!

It all started when the entire contents of our household goods arrived in Spokane after our move from Anchorage, Alaska. We found that there was a pile of goods that just didn't have a place in our new home, and my husband looked up our local branch of The Arc to see where we could drop off a donation to an organization that we both loved.

On the website, was a job vacancy for an Individual Advocacy Coordinator. "You'd be great at this," he said, and with a little self-reflection, I agreed. I needed to work for a nonprofit in which I had shared values. I am skilled at helping people gain knowledge, skills, and resources, and I like solving problems. Working for The Arc was a natural fit for my skillset and mindset. One month in, I know I made the right decision to join the Advocacy & Family Support team.

#### So, what does advocacy mean?

Sure, there's Meriam's definition: *ad vo ca cy; the act or process of supporting a cause or proposal*. Other dictionary definitions aren't much different. What I've found, however, is that our advocacy work at The Arc of Spokane is a bit more complex and much more specific.

As an Individual Advocate (IA), my job is to help people with intellectual and developmental disabilities access resources and navigate challenges. I've come to learn that the real work of an IA aims to make the community more accessible, lessen barriers, and enhance the quality of life for folks with IDD and their families. Where there's a barrier or challenge, we work to find and advocate for solutions.

#### What does that look like?

Each day at The Arc has been totally different! One day, I helped someone who needs to build their social life and skill set after they've graduated from school. Another day, I learned about resources available for an adult who needs mental health services. On the next, I delved into what housing resources are available to individuals with unique needs.

Simultaneously, I'm watching my colleagues prepare for trainings like Life After High School and gear up for advocacy on the political stage in Olympia. Every day is busy with meaningful work.

#### Why does it matter?

It matters for me because of that last bit: meaningful work. Who doesn't want a job where you can honestly say that you made someone's life a little better? That is every day in Advocacy & Family Support. I feel a connection with everyone I help. Their challenge becomes my passion that I work to find resources and solutions for. I learn along with them as we sort through options and weigh the possible outcomes. I never have the perfect answer; but usually, I can help my clients see their options and make informed decisions for themselves. Every day, I get to meet amazing people in the IDD community, hear their stories, amplify their voices, and give them a little help. And *that* is a good way to spend a day at the office.

Now, a month into the job, I'm still overwhelmed with all that I need to learn about the IDD world. But I know how to respond when people ask me about my job. I simply say, "I get to work every day to make the world a little better for people with IDD."

# The Importance of Support Networks for Resilience

# Blaine Huizinga Sexual Abuse Awareness and Response Trainer

Do you recall the first time you fell down and hurt yourself? If you're like me, you probably don't. However, there was likely someone (most likely a parent or adult) there to assist you. Someone who cared about your feelings and reaction and who helped you to heal from the experience.

Or perhaps you didn't have someone around to comfort or empathize with you. Maybe instead, you had to realize what was happening, process your own reaction, which may have included crying or yelling, and eventually you learned how to recover.

In either case, while this experience probably didn't leave a lasting impression on you, it may have allowed you to figure out who you could rely on for help, relate to your painful experience, and engage in processing your reaction to trauma.

That experience laid the groundwork for your resilience*: your ability to adjust and heal from trauma*. While not the same gravity of situation, people who've experienced sexual violence can have those same needs: a need to lean on others for support, someone to care about their feelings and reactions, and calm healing support to process the experience. This is likely not just one person to fill all these roles, but rather a support system within a community. Without these supports available, healing from harm can be stalled or may simply not occur.

For folks with intellectual and developmental disabilities (IDD) who've experienced sexual abuse, they may face those same struggles, as well as additional barriers such as not being believed., Due to misinformed opinion, folks with IDD are not taken seriously or seen as credible witnesses. They may be told that their choices led to them being abused, which is unhelpful because the simple fact is that no one can have actions that merit sexual abuse. Sometimes, they are not offered confidential options in their own recovery.

It's often the case that others close to the person may not recognize changes in their behavior, activities, or demeanor could be the result of trying to cope with trauma that has occurred. It's also quite common for people to deny that this could be the case, simply because the thought of harm is so very frightening.

So, what helps someone to heal in the aftermath of abuse? Empowerment, voice, and choice.

Whether it's sexual abuse, domestic violence (which includes both intimate partner violence and violence from those inside the home or relatives, or other forms of harm, they all share a commonality: an *abuse of power & control.* 

When folks have experienced harm, they experience disempowerment. Choice has been taken away. When people are given options and direct access to support, they can reclaim their voice and power of choice, which can restore that sense of empowerment.

People who've been harmed can access community support services like victim advocacy (someone who can be present during Adult Protective Services or law enforcement investigations, civil or criminal court processes, help someone to file an emergency protection order, or at the hospital emergency room for a sexual assault forensic exam) to know their rights and what choices they have, gain counseling/therapy to address the impact trauma has had on their mental health and wellbeing, and forge connections to others in the

community. They can gain help establishing a set routine (hobbies, employment, or volunteering) with consistency. These all can be helpful in re-establishing some of the normalcy of life before the trauma occurred. Those relationships, whether personal or professional, can be helpful in just checking in to see how someone is doing, offering comfort or distraction, and validating their response and feelings.

While someone may not have access to this wide network of people already in place, it's important to recognize how invaluable even a few of these relationships can aid in trauma response and recovery. The more folks with these connections can recognize potential signs of abuse and assist those who have IDD to get help.

Having meaningful human connections vastly increases someone's resilience when trauma occurs. Just as we hope that there's someone available to pick you up when you fall, we hope that those who've been harmed by violence have access to the healing support and non-judgmental validation of their choices and individual steps taken towards their own recovery.

# ADVOCACY ALERT Tell Congress: Care Can't Wait!

People with disabilities rely on Medicaid home and community-based services (HCBS) to live independently in their communities. HCBS help people with disabilities with everyday support, like getting around the community, employment supports, dressing, bathing, taking medication, and much more!

But due to the fact that Medicaid must fund institutions, and home and community-based services are optional, states don't have the funding to support everyone in the community. This means that:

- Over 650,000 people are stuck on waiting lists,
- Direct care workers are underpaid due to stagnant wages, and
- Too often unpaid family caregivers are filling in the gaps in service it's a crisis!

We need Congress to take action NOW. Raise your voice and share your story here.

### Company partners with Disney for pop culture wheel cover designs

Izzy Wheels was founded by Irish sisters Ailbhe (pronounced Alva) and Izzy Keane.

In 2016 Ailbhe, who was studying at The National College of Art and Design (NCAD), chose to design a range of removable wheel covers that matched her sister's colorful style. The idea was inspired by Izzy, who was born with Spina Bifida and is paralyzed from her waist down. Izzy has always seen her wheelchair as a symbol of freedom but never felt it expressed her personality. The company motto is "if you can't stand up, stand out!"

Their company has now joined forces with Disney to launch a collection of wheel covers that include characters from Disney, Marvel, and Star Wars. Learn more about the wheel covers <u>here</u>.

### Labor Department expands disability employment initiative

Federal officials are looking to promote changes in state policies and systems in order to increase competitive integrated employment among people with disabilities. Read the full story <u>here</u>.

### View new resources in The Arc's Virtual Program Library!

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.

### 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 <u>here</u>.

# **Resource Spotlight through The Arc**

Did you know The Arc of Spokane has a digital resource guide? Click <u>here</u> 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 <u>advocacy@arc-spokane.org</u> 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 <u>advocacy@arc-spokane.org</u>.

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