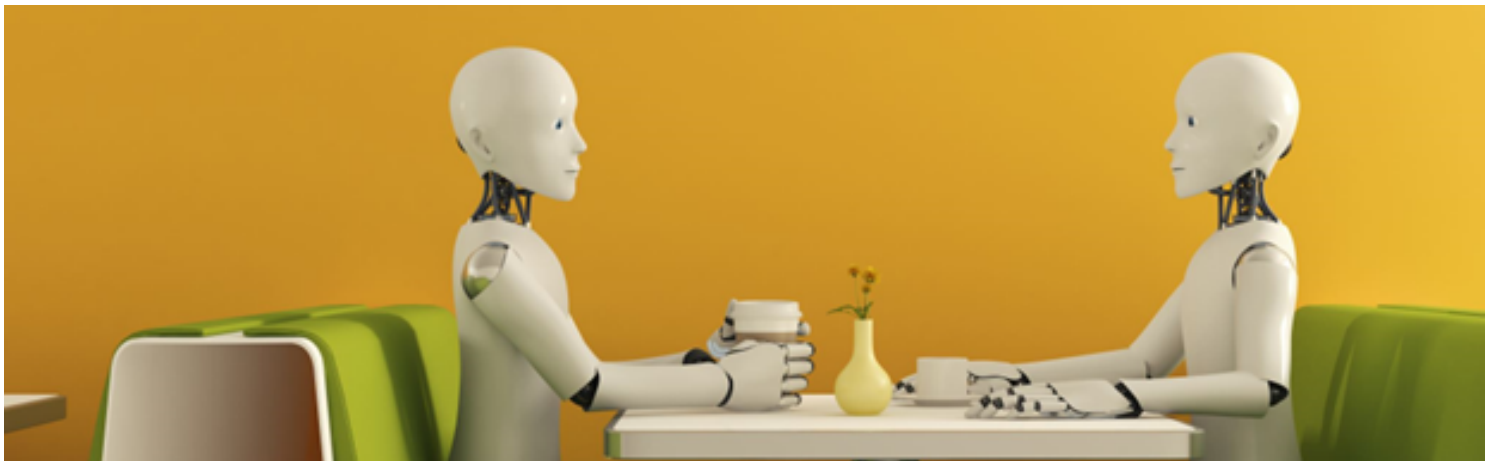




COMMUNITY CONNECTION

in partnership with



SITTING IN UNCOMFORTABLE SPACES

by Tami Leitz, Spokane County Parent to Parent Coordinator

I took Claire (my teenage daughter with Down Syndrome) out to lunch recently. Our server was so obviously afraid of Claire that she started talking quietly, backed up, and looked to me to rescue her as if I had brought an aggressive animal into the restaurant. Claire's sister jumped in to translate the order as the woman was speaking too quickly and quietly for Claire to understand. I stopped the rescue attempt to provide Claire the opportunity to finish ordering her food herself, going against my automatic response, which would have been to end this incredibly uncomfortable interaction as quickly as possible. It would have been easy for me to get upset about this woman's ignorance or jump in to ease her discomfort. Sometimes the answer is neither.

Sometimes I can choose to sit in uncomfortable spaces, allowing a stranger to experience humanity in another person. The server's inability to engage with a person with a disability was not hate, it was shame. The world we live in demands sameness. It pushes people who cannot conform so far into the margins that most of us forget they exist. *Until we dismantle the belief that human dignity is not conditional, people who are different than us will continue to trigger shame.* Once shame is in the picture it becomes very hard to see ourselves clearly. The interaction is no longer about taking a food order from a person with Down Syndrome but fighting back uncomfortable feelings. Instead of reflecting on why we are so caught off guard, we attack or flee from the person who made us feel something unpleasant simply by existing. There is no room for self-reflection, only blame. The young woman taking Claire's order had probably never interacted with a person with a disability before, felt embarrassed about it, and instead of pushing back against that feeling got overwhelmed with shame.

There is nothing quite like the experience of going to someone in a position of power who says they want to support people with disabilities and instead of receiving the help you so desperately need and deserve, receiving harsh criticism and rejection instead. Too often the people who are making decisions on behalf of the disability community have no personal experience with disability. They have built their lives and careers around being good and moral people. They like the idea of liking people with disabilities and do not recognize the harm their idealism causes. Trying to have a conversation with someone fighting their unacknowledged shame around disability is often a losing battle because pointing out issues like discrimination can make people defensive, rather than compassionate.

I might go to my church and say, "Because there is not enough support for my child in Sunday school, I am getting called to pick her up and neither one of us has been able to go to church in months. Can we please get some extra volunteers in that room so everyone can go to church?" If the leadership is coming to this conversation without the understanding that sometimes good intentions cause harm, what works for most people don't make it the only way or the best way, and the willingness to believe an experience that is different than their own, they might hear, "What you are doing is not good enough. You don't care about people with disabilities" instead of a heartfelt concern and bid for connection.

To truly listen to someone who is marginalized we must develop the skill of holding space without judgment. People who walk through life with the understanding that they do not indeed know all the answers and acknowledge that life is complex (there is no right answer for every situation) start off miles ahead of their peers.

Over time I have met people who empathize with our experience. Maybe they were stepparents and could relate to the complexities of Claire not being my biological child. Sometimes they had experienced some other form of systematic oppression and discrimination and could understand that often systems are not set up for everyone to succeed.

Remarkably, some people have the capacity to observe an experience, listen, and choose to believe, even when they have no frame of reference from their own lives. This isn't because these people are inherently better than others. I believe one reason is because they choose to see value in a person's humanity and not their perceived value in society.

When I spent all my energy on perfectionism and achievement I got pretty upset when my sibling with a disability did not follow along. So much so that I was mean and critical, which caused harm in our relationship I still feel the effects of today. I could not access empathy or compassion because I was too worried about following the rules. It didn't matter that following the rules was not attainable for him. If I was working this hard to do what everyone else was doing, so should he. I thought that accommodations were an unfair advantage. I believed that nothing was more important than being good and if you could not you were not trying hard enough or didn't care. I felt all of that only as discomfort but didn't stay with the feeling long enough to realize I was attacking my brother for making me confront my dysfunctional coping strategies and perfectionism.

I could not extend compassion to my sibling beyond the compassion I was giving myself. When we attach our worth to performance, need to win, fear other people's judgment, can't ask for help, can't tolerate mistakes or uncomfortable feelings we will never be able to extend compassion. To experience growth and freedom we will have to experience vulnerability and discomfort. We will have to stop showing the world a highlight reel and allow the hardest parts of ourselves to be loved. We must reframe what gives life meaning. Humility doesn't make us weak; it is the birthplace of love, curiosity, courage, and hope. To build a better world for every person we must start with loving our whole messy selves. We ask ourselves, what uncomfortable feelings are coming up for me?

Am I making this about me and the way I am being perceived? Can I tolerate this discomfort to make space for growth and understanding?



QUIT RAINBOW WASHING

How Agencies can be Better Allies to the LGBTQIA+ Community

*by Megan Juneau, Advocacy & Family Support Manager
with Tami Leitz, Spokane County P2P Coordinator and Courtney Anderson, DEAI Manager*

It's June again, and that means I'm back on my soapbox talking about the ways in which we can better support individuals of all identities. As you've probably noticed, this is the one time every year where the Internet, storefronts, and sidewalks are littered with rainbows. While I'm sure agencies rolling out webpages, logos, and merchandise with rainbows that "Celebrate Pride" during the month of June is with good intent, as a queer person, I never look at those efforts and think, "Wow, they support LGBTQIA+ folks - good on them!"

Instead, I think "I wonder if they are actually a queer-friendly agency," or "What are they actually doing to support LGBTQIA+ folks?", or "This looks like rainbow capitalism!", or even "But do they actually HIRE people from the LGBTQIA+ community?"

Using the rainbow is performative - being an ally is a 24/7/365 job.

Instead, I think what is most helpful is to do our own personal work to identify our own biases, expand our knowledge of the history, experiences, trauma, and barriers people of marginalized communities face, and pledge to strong allyship by taking concrete steps for action that improve the quality of life and amplify the voices in those communities.

It's important that agencies don't look to people that identify as members of these communities to educate them. Much of this work can be effectively started on your own. And just because someone is a member of a particular community does not mean it's appropriate to call on them to inform you, does not mean they are an expert, does not mean that they want to represent an entire community, and it does not mean they want to speak on behalf of others' lived experiences. Agencies must do this work **on their own time, on their own dime**. If you do ask someone to use their lived experiences and knowledge to teach you, you should pay them for it. One employee does not represent an entire population. Every human is an individual and cannot speak on behalf of any other person or community. Using one person as your "expert" without paying for their opinion is exploitation.

UNDERSTANDING OF ONESELF AND IDENTIFYING BIASES

First, I think it's important that we understand where we as individuals sit on the spectrum of understanding inequity and bias and having awareness of oneself. There are a ton of great platforms like YouTube and LinkedIn Learning where you can gain some foundational knowledge of your unconscious biases and your role in perpetuating marginalization, inequity, discrimination, and harm to others.

After you get a sense of what you do and don't know, [Harvard's Implicit Association Test](#) provides additional insight into your current biases.

Additionally, here are some recommended resources to dive into.

Watch:

- Ro Haber's *Stonewall Forever: A documentary about the Past, Present, and Future of Pride*
- [What is intersectionality?](#) by Professor Peter Hopkins
- TED Talk [The Urgency of Intersectionality](#) by Kimberlé Crenshaw
- *13th*, Ava DuVernay's documentary on Netflix
- *Crip Camp: A Disability Revolution* on Netflix

Read:

- *Blindspot* by Mahzarin Banaji
- *Race Talk and the Conspiracy of Silence* by Derald Wing Sue
- *So You Want to Talk About Race* by Ijeoma Oluo
- *Uncomfortable Conversations with a Black Man* by Emmanuel Acho
- *Normal Life: Administrative Violence, Critical Trans Politics, and the Limits of Law* by Dean Spade
- *The New Jim Crow: Mass Incarceration in the Age of Color Blindness* by Michelle Alexander

Last June, I wrote an article about intersectionality that I'm still very proud of and think is a helpful tool to begin understanding intersectionality and how we cannot "celebrate" one community without celebrating others. Consider reading the article [here](#).

EXPANDING YOUR KNOWLEDGE

The most effective way we can expand our knowledge is through exposure; exposure to different people, backgrounds, cultures, identities, and experiences. We are only *aspiring* allies until we have some level of cultural humility, a desire to understand one another, and true empathy for ourselves and our communities. Here are some incredible resources that can guide you through a process of self-reflection and self-actualization and evoke true systemic change.

Read:

- *Being Heumann: An Unrepentant Memoir of Disability Rights* by Judith Heumann
- *Capitalism & Disability* by Marta Russell
- *Crip Kinship: The Disability Justice and Art Activism of Sins Invalid* by Shayda Kafai
- *Demystifying Disability: What to Know, What to Say, and How to be an Ally* by Emily Ladau
- *A Disability History of the United States* by Kim E. Nielsen
- *Disability Visibility* by Alice Wong
- *Solen Bodies, Reclaimed Bodies: Disability and Queerness* by Eli Clare
- *Read This to Get Smarter: About Race, Class, Gender, Disability & More* by Blair Imani

- *Disability Pride: Dispatches from a Post-ADA World* by Ben Mattlin
- *My Body is not a Prayer Request: Disability Justice in the Church* by Amy Kenny
- *A Quick and Easy Guide to Sex and Disability* by A. Andrews
- *The Ultimate Guide to Sex and Disability: For All of Us Who Live with Disabilities, Chronic Pain, and Illness* by Cory Silverberg
- *Uprooting Racism: How White People Can Work for Racial Justice* by Paul Kivel
- *Exile and Pride: Disability, Queerness, and Liberation* by Eli Clare

People to follow:

- Annie Segarra | Twitter and Instagram | @annieelaine
- Aaron Rose Philip | Instagram | @aaron_philip
- Haben Girma | Twitter and Instagram | @habengirma
- Molly Burke | Instagram and YouTube | @MollyBurkeOfficial
- Russell Lehmann | LinkedIn and <https://russl.co>
- Morgan | Twitter and Instagram | @neurodifferent
- Chella Man | Instagram | @chellaman
- Max Siegel | LinkedIn
- Eddie Ndopu | Instagram | @eddiendopu
- Samantha Renke | Instagram and Twitter | @samantharenke
- Ellie Middleton | LinkedIn
- Lauren "Lolo" Spencer | Instagram | @itslololove
- Nicole Parish | Instagram and TikTok | @_soundoftheforest_
- Shane and Hannah Burcaw | YouTube | @squirmyandgrubs
- Ella Willis | LinkedIn
- Tami Leitz | TikTok | @not_a_mild_salsa
- Alyssa Higgins | Instagram | @wheel.life.in.the.wheel.world
- Erin Novakowski | TikTok | @WheelieErin
- Alex Dacy | Instagram | @wheelchair_rapunzel

Media outlets to subscribe to:

- The Advocate
- Cripple Media
- The Grio
- LGBTQ Nation
- Autism Eye
- Pink News
- Open Future Learning (on LinkedIn and Facebook)
- Pride
- Atlanta Black Star
- Disability Scoop
- Washington Blade

TAKING ACTION

Here are some concrete action steps you can take to be a true ally for the LGBTQIA+ community.

1. Pay people appropriately when asking them to provide consultation and guidance on developing agency best practices and ensuring you're creating safe, inclusive spaces for employees and constituents. Lived experience, education, and expertise is not free.
2. Pledge to be strong allies and engage in diversity, equity, access, and inclusion (DEAI) work year-round. That could look like sharing your pronouns in your email signature, beginning meetings with introductions of self, name, and preferred pronouns, commit to using gender-inclusive language, hire a DEAI consultant to ensure your organization is providing employment and leadership opportunities for LGBTQIA+ members, supporting LGBTQIA+ causes with organizational money and campaigns, develop organization's core values that reflect diversity and inclusion, and ask what's missing and how can we do more.
3. Enroll in LinkedIn Learning's course "[Understanding and Supporting LGBTQ+ Employees](#)"
4. Become familiar and engage with current legislation impacting marginalized communities. While U.S. specific, the American Civil Liberties Union (ACLU) is currently tracking [336 anti-LGBTQ+ bills](#) in the United States, including 26 bills in at least 14 states that could criminalize the art of drag. [Jonathan Hamilt](#) writes, "Additionally, companies should amplify their opposition to anti-LGBTQ+ bills. Whether it be through denouncing the legislation in public statements, hiring Drag Story Hour for a company-wide event, or donating money to anti-discrimination groups, use your massive reach and voice to nudge social justice forward. When you start making space for everybody, that means more voices can have an equitable space to innovate and express creative ideas. And if people feel safe in these spaces, that's when the magic happens."

Of course, if anyone wants to discuss these concepts further or would like to be connected to additional resources, please contact The Arc at advocacy@arc-spokane.org.



US vs. THEM: The Problem with "Othering"

by Stephanie Sherman-Petersen, Spokane County Parent Coalition Coordinator

Inclusivity within our communities is the basic tenet of The Arc of Spokane. Being seen, heard, understood, valued is what inclusivity means to us as humans. When our community members with intellectual and developmental disabilities can share in activities, engage in employment and volunteer opportunities, attend concerts, visit libraries, access governmental rights, and truly be a part of our communities, we are able to recognize each other's human worth. Seeing each other, helping each other, communicating with each other, makes community.

With this ideal at the forefront of my mind, I am saddened to come across divisive and ableist language so often. In a recent article about the need for affordable housing, folks generalized houseless people among us as being thieves and criminals. A prominent social media influencer pronounced that "we've gone too far with this inclusivity thing" when she saw an ad featuring a disabled model who uses a wheelchair. At a local school board meeting, parents complained about the time delays and cost of providing specialized access to bussing for individuals who need assistance. When we grow accustomed to *not* seeing people with disabilities, with different needs, we forget that they are a vital part of our community. When we don't see, we don't understand, and we sometimes fear. Those with differences become "the others."

No wonder since whole generations of Washingtonians have grown up not seeing people with disabilities among us. Children with intellectual and developmental disabilities in our public schools are "the others," isolated from their peers throughout their formative years. "Others" have been sent away to be confined in archaic state-run institutions that are hours away from their home communities. Only with deliberate advocacy do people with disabilities have full access to community life. Segregation of a whole population continues to be the norm, despite the startling statistic that 25% of us have a disability.

This 25% statistic actually gives me hope and drive going into the next legislative session. **25%!** The Disabled Vote is one of the largest voting blocs, crossing all facets and sectors of the community. Self-advocates, allies, and family members of people with IDD can unite in a common purpose: to make inclusion the norm rather than the anomaly. Closing state-run institutions and Nothing About Us Without Us are two important legislative goals that will require representation – will require that all are seen and heard in our communities. We can make good things happen, turning othering into inclusion, together.

As always, here's my invitation for you to join us in IDD Advocacy!

Join our Inland Northwest Disability Action Bloc Facebook group where we share information about legislative issues, empower those with disabilities to have their political voices be heard, and rock the disability vote:

<https://www.facebook.com/groups/211365574429833>

Join the Spokane County Parent Coalition and serve as an advocate and thought leader for guiding the County's work on behalf of all people with IDD to promote an inclusive community that *celebrates* diversity:

<https://www.arc-spokane.org/parent-coalition>

PSYCHOLOGICAL SAFETY & RELATIONSHIPS

by Blaine Huizinga, Sexual Abuse Awareness and Response Trainer

There's a lot to be said for parents of children with IDD. Often parents work hard to create a safe and supportive environment for their child to grow and thrive. As far as I understand, this can sometimes feel like an overwhelming & isolating task. There are times, however, that when trying to safeguard our kids, we may inadvertently not recognize our role in shaping or influencing their behavior with our own personal views about relationships & sexuality. This can, in turn, cause distress and distrust when it comes to when, eventually, they want to have intimate partner relationships.

Take the following as an example: Recently, as part of my role at The Arc of Spokane, I was presenting to a group of parents about healthy relationships, abuse awareness, Dignity of Risk, relationship autonomy for those with IDD, and someone's right to choose who to tell if they've been sexually abused. During the discussion following the presentation, one parent spoke up to share that when they checked in with their adult child, their child said they would not want to share about the abuse with their parent. The parent was very surprised to learn that this was the case and wanted to understand if this experience was very common. I validated that many folks across the neurodiverse & neurotypical spectrums don't want to disclose if they've been harmed, much less to their parent.

This parent's response is not uncommon. When folks provide care for their loved one with IDD, it can be easy to assume that because you may want what's best for them, that they should want to feel comfortable telling you if something goes wrong. What's damaging is when we **feel entitled** to this disclosure. Confronting that someone may be experiencing harm and yet decide to not share with you can obviously be very frightening, however, it's important to remember that it's someone's choice who they share that information with. It is a current understanding within the field of psychology that disclosing abuse before one is ready or comfortable is psychologically damaging.

How does psychological safety come into play here? When someone is abused, they often feel a lot of guilt and shame over the situation. It can be such a violating experience that keeping it a secret feels much safer than having to explain what happened. This guilt and shame can be exacerbated when you know this information could damage a relationship you regard as positive: whether it be a parent/caregiver, intimate partner, sibling, friend, etc. After experiencing abuse, folks can feel like they won't be believed, be blamed for somehow causing the abuse, or just not being taken seriously. The response to their disclosure can also lead folks to regret telling their loved one if the loved one has an intense reaction, tries to take matters into their own hands against the abuser, or worse, blames the person who told them of abuse for "doing the wrong thing in the moment" for whatever reason.

Psychological safety allows for someone to not be judged, reprimanded, or made to feel shame for expressing what they feel. By remaining non-judgmental, folks who hear about abuse can learn to support the person regardless of their feelings or discomfort at hearing the news. As much as it is unsettling to hear about abuse, imagine how much worse it would be to experience it.

It's easy to assume that, based on the nature of a relationship, one should automatically feel some sense of psychological safety with their loved ones. There can be barriers to this, however unintentional or intentional. For instance, it can be common for folks to insert their own opinion about someone's relationship with another person, or comment on their abilities or lack of ability to make sound decisions. These remarks, however, are not supportive of one's autonomy: one's ability to make one's own decisions. It likely has the opposite effect: resulting in them feeling less empowered and more defensive about their abilities as well as less receptive to input from this person.

If we want to truly reach folks, we need to understand the impact and importance of psychological safety when it comes to trusted relationships in their network of support. If our goal is to be that supportive person, then we

need to share concerns, thoughts, and feelings in a way that supports someone's dignity to take risks and sometimes make choices that may result in negative consequences. If something does go wrong, someone is more likely to tell someone they trust rather than someone they feel judged by.

Stopping oneself from expressing one's immediate thoughts can seem like a daunting task, but it's vital to preserve a relationship where there is psychological safety. There are many ways and instances when parents already do this, but often when it comes to discussions around relationships, sex, and sexuality, it can become easy to forget about reserving one's judgment. There's a difference between teaching/encouraging healthy relationships (including sexuality) and expressing our own wants or preferences for someone's chosen partner. By focusing on the former, we can further strengthen someone's confidence to identify harm, speak out against it, and trust those around them who want to help.

We can encourage this safety and promote autonomy by explaining that if harm does occur, people have options to report the abuse and get help. These include telling a caregiver, trusted adult (make a point of explaining that we don't need to confide in the person causing the harm), Adult/Child Protective Services, caseworker, teacher, counselor, victim service provider (like a community-based advocate at a sexual assault program), etc. Giving these options can restore a sense of control back to the individual who experienced harm, as well as empower them over the abuser by having a say in how they get help. Empowerment, voice, and choice are those key tools for not just relationships, but also for promoting healing, independence, and reducing isolation.



SUMMER WITH A PURPOSE

Summer With a Purpose (SWAP) hosts a range of exciting activities and outings around the Spokane area to provide social engagement, personal enrichment, life skills development, and of course, fun for individuals with intellectual and developmental disabilities (IDD) ages 12-21!

Check out the range of activities currently available beginning June 23 at www.arc-spokane.org/swap, and don't forget to come back often as more are added throughout the summer!

Receive a free Arc@School Curriculum Scholarship

The Arc of Spokane wants you to know how to confidently navigate often complex and difficult IEP and 504 conversations when advocating for your child in school!

The Arc is providing 40 FREE Arc@School curriculum scholarships to help family members of individuals with intellectual and developmental disabilities (IDD) learn the intricacies of the system.

These scholarships are valued at \$99 and fully cover the cost of this eight-module course. Get ready to learn, at your own pace, how to advocate using successful strategies.

You will receive an email from the Arc@School with your username and password within 4-5 business days of registering.

Questions? Contact Tami Leitz at (509) 789-8782 or by email at tleitz@arc-spokane.org.

Register [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 [here](#).

Find local resources for the help you need!

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.

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