

Spotlight:

Disability Justice

An annual publication from End Domestic Abuse Wisconsin exploring pathways to ending violence

In *Care Work: Dreaming Disability Justice*, Leah Lakshmi Piepzna-Samarasinha reminds us that “[**disability justice**] means we are not left behind; we are beloved, kindred, needed.”

With the onset of COVID-19, a mass disabling event which also saw a global domestic violence (DV) pandemic, there was a collective turning towards solutions and ideas already cultivated by the disability justice (DJ) community as folks sought creative ways of access, support, and care. For many, this highlighted not only the brilliance and beauty of DJ, but also the systemic marginalization of those living in sick and disabled bodyminds.

We hope this report provides **clarity** on concepts that may be new or only vaguely familiar to many in this field; **connection** to how critical DJ is to all working towards safety and dignity for survivors of DV; **resources** to go deeper and challenge assumptions; and **guidance** for putting DJ principles into motion.

With this report, we do not claim our practices and policies yet reflect DJ principles. Our work is only in its beginning phases as we bring DJ to fruition in our daily work. Still, we commit to change and growth as we intentionally shift our awareness and norms.

I often say: “Community is Medicine.” We recognize our beloved responsibility and desire to center work by and for disabled folks living at the margins of race, class, gender, and resource access as we cultivate authentic community, heal, and create violence-free futures. We have work to do — work that is impactful, important, long-term, and supportive of the future we want to see, where no one is left behind.



December 2022



INSIDE THIS ISSUE

| | |
|--|----|
| Introduction | 2 |
| Community Survey | 4 |
| Community Stories | 8 |
| Spotlight: Nancy Yang | 18 |
| Care Work Book Group Discussion | 22 |
| Sami Schalk | 28 |
| Elder Abuse Intersections | 30 |
| Guardianship | 32 |
| TS Banks | 33 |
| Resources | 34 |
| Kay Ulanday Barrett/2023 Teen Summit | 42 |
| Staff & Board | 43 |



**Executive Director
Monique Minkens**

Introduction

This exploration of disability justice began with several questions: How do we define disability justice (DJ)? Why are we bringing it to the forefront at this time? How do we understand DJ in the context of our work to end violence? Who is leading this work in Wisconsin?

For this publication, we gathered resources to help us collectively learn more about Disability Justice, to apply its principles to our central mission of ending violence, and to help us get closer to embodying DJ in our work.

How do we define disability justice? The following definition, taken from [Disability Justice - a working draft](#) by Patty Berne, has been greatly shortened. I urge you to read it in its entirety.

Disability justice honors the disability rights movement for its many successes in advancing a philosophy of independent living and establishing civil rights for people with disabilities, while also naming its flaws – among them, its single-issue identity basis and historical centering the experiences of white people and those who have access to a legal or rights-based framework.

In response, disabled activists of color, originally queer women of color incubated in progressive and radical movements that did not systematically address ableism, developed the DJ framework in 2005.

DJ work, largely done by individuals within their respective settings, is led by people of color and of queer and gender non-conforming disabled people. DJ asserts that able-bodied supremacy has been formed in relation to intersecting systems of domination and exploitation – heteropatriarchy, white supremacy, colonialism and capitalism, each system co-creating an ideal bodymind built upon the exclusion and elimination of a subjugated “other” from whom profits and status are extracted.

A DJ framework understands that all bodies are unique and essential, with strengths and needs that must be met; we are powerful not despite the complexities of our bodies, but because of them: all bodies are caught in these bindings of ability, race, gender, sexuality, class, nation state and imperialism, and we cannot separate them.

Disability Justice is a vision and practice of a yet-to-be, a map that is being created. [DJ work aligns with its ten principles](#), each offering new opportunities for movement builders working towards a world in which every body and mind is known as beautiful.

(Continued on page 3)

Why are we bringing DJ to the forefront at this time?

We have all learned from the pandemic: older people and people with certain disabilities were more vulnerable to developing life-threatening illness from Covid-19; long covid emerged as a disabling condition; people learned from the disability justice community that we could manage meeting and working from our homes, adapting to the circumstances of the pandemic in ways that disabled people had been doing pre-pandemic. Even while isolation made people more vulnerable to abuse, connecting remotely also meant easier access to spaces. We saw the disability justice community leading and teaching us online.

How do we understand DJ in the context of our work to end violence?

To get a sense of where our communities were situated with DJ, we invited individuals and organizations in our networks to participate in a short survey and share their stories with us. You'll find the stories of those who gave permission to be identified, beginning on page 5, along with summary responses to the survey.

Predictably, reviewing resources and discussing content led to more questions than answers. Many points at which disability intersects with domestic abuse and violence are clear. We know that there are higher rates of abuse among disabled people. Aging, disability and abuse intersect in specific ways. Legal guardianship (page 32), plainly an opportunity for one adult to exert abusive control over another adult, is both a domestic abuse and disability justice issue. Domestic abuse can be disabling – for example, brain injury, as Kathy Connolly and Michelle Ruhl-Ortiz share in a recorded

(Continued on page 4)

"There is no neutral body from which our bodies deviate. Society has written deep into each strand of tissue of every living person on earth. What it writes into the heart muscles of five star generals is distinct from what it writes in the pancreatic tissue and intestinal tracts of Black single mothers in Detroit, of Mexican migrants in Fresno, but no body stands outside the consequences of injustice and inequality...What our bodies require in order to thrive, is what the world requires. If there is a map to get there, it can be found in the atlas of our skin and bone and blood, in the tracks of neurotransmitters and antibodies."

– Aurora Levins Morales, Kindling

webinar, occurs more frequently than has often been recognized (page 37). We could identify many more of these intersections, crucial for cross-movement work, to embody DJ in work to end violence.

Disability justice holds these realities. There is a confluence of movement work in this moment: domestic abuse is linked to all forms of violence; transformative justice and disability justice are not separable from a movement to end sexual and domestic violence. The systems and structures that we work within each day do not readily change to embody the principles of disability justice, and we already have enough work to keep us quite busy. We are cautioned against “throw[ing] around the word ‘disability justice’ on the list of ‘justices’ in [our] manifesto” (*Care Work: Dreaming Disability Justice*, Leah Lakshmi Piepzna-Samarasinha) and thinking we are done. DJ is not an add-on; we as a collective do not have a choice – ability and disability are fluid. Together we are many disabled and abled people—disability justice is for us.

Among the many resources we discovered, ***Disability Justice: An Audit Tool*** became key to understanding how far we had to go to meaningfully shift to a DJ framework. The Audit Tool, created by Leah Lakshmi Piepzna-Samarasinha, is available as a [free download from the Northwest Health Foundation website](#). An example of moving sustainably toward practicing DJ is offered within this toolkit: Using the 10 *Principles of DJ Discussion Questions* (p.21 of the Toolkit) to reflect on one principle each month, examining how we are embodying it and where we need to grow. This seems like a good place to start.

Who is leading DJ work in Wisconsin? Included in this publication are spotlights of Nancy Yang, Dr. Sami Schalk, and T.S. Banks. There are more individuals than could be included in this limited publication, and certainly many more who we hope to find in the future. The list of resources features some of the national leaders. We have drawn extensively from the work of Leah Lakshmi Piepzna-Samarasinha, in particular. We are thankful to our friends and colleagues at Disability Rights Wisconsin, who discussed ideas and offered suggestions, and to all of those who shared their time and stories with us for this publication.

– Colleen Cox, Editor

This publication was developed by End Domestic Abuse Wisconsin staff:

Elise Buchbinder, Director of Communications; **Colleen Cox**, Education and Training Coordinator; **Sara Krall**, Homicide Prevention Program Director; and **Sara Mayer**, National Clearinghouse on Abuse in Later Life Assistant Director.

Community Participation: Summary and Stories

Organizations in the early stages of bringing disability justice into their work often start by adding in some access—making sure meeting spaces are wheelchair accessible, hiring ASL interpreters, etc.—but disability justice is about more than adding access. It is also about shifting power.

To get a sense of where our communities were situated with disability justice, we invited individuals and organizations in our networks to participate in a short survey and share their stories with us. Many thanks to those who participated. Below are selected survey questions, quotes, stories, and names of those who gave permission to be identified. Stories have been edited for clarity, and are found in text boxes throughout the publication under the heading “Stories Matter.” Survey questions are in the text box (right); complete survey data (32 responses) can be viewed at

[EndAbuse DJ Survey Data All 2022.pdf](#).

When you think of disability, what comes to your mind? The quotes below capture some of the many thoughtful responses.

- Expansive. Most of disability is unseen, unknown by able bodied people.
- Disabilities affect people physically and/or mentally. When someone has a disability, the world may not be as accessible to them. **The world is built for neurotypical, able-bodied people.**
- Community. Culture. Adapting. Accommodations. Ableism. Neurodiversity. Interdependence. Behavior as communication. Can be innate (e.g., Autism or Down Syndrome) or acquired (e.g., spinal cord injury or traumatic brain injury). Subjective - what's disabling to one person may not be disabling to another (e.g., mental illness). **Variable / Not constant - a person's level of energy/disability/spoons can vary and being able to do something once doesn't mean you can do it again.** Consent. Trauma.

(Continued on page 6)

Questions

- *When you think of disability, what comes to your mind?*
- *How have you seen ableism show up in your work?*
- *Are disability justice conversations already happening at your organization? What are some examples?*
- *What do you see as your agency's biggest challenge in infusing more disability justice concepts into your work?*
- *What are your training and technical assistance needs related to disability justice, and how might End Abuse support your efforts?*
- *Please share your stories about your own experience living with a disability, and disability justice from your perspective.*

(Continued from page 5)

How have you seen ableism show up in your work? About 80% of people shared specific examples of ableist impacts on clients or staff.

- When my team decides to walk someplace, and I am left behind or not able to join them. When someone tells me that I look strong and healthy and don't act disabled.
- The expectation to be on-call doesn't account for differences in humans' ability or capacity to professionally show up at all hours of the day/night.

- **Coalitions planning events at the Capitol without thought to mobility.**

- People with certain disabilities accused of being drunk or high.

- Stating that we aren't the appropriate organization to serve someone because they have an intellectual disability.

- **Complicated language / paperwork without adequate support to ensure informed consent.**



- Focus on IPV limits access to disabled survivors where the abuser is a caregiver, not an intimate partner.
- **People not believing self-reports of disability or reports of other info because of disability (e.g., "he's confused" or "she's just cr**y").**
- Lack of access to places/spaces, lack of interpretation services...offering virtual trainings but not asking in advance if participants require any special accommodations. The assumption that every participant can see, hear and/or engage at the same level is problematic.

(Continued on page 7)

Are disability justice conversations already happening at your organization? What are some examples? Twelve people offered examples.

- We have brought in trainers specifically about trans disabilities, immigrant issues with disability services, jails, etc. We have a couple very vocal staff on this topic.
- I would say in a way, yes, since we serve the Deaf and Deafblind Community, so we are working on making things better and more accessible to the best of our ability.
- My director is open about her disability, so we weave these issues into our daily work.
- **We created our text line based on the knowledge that hard of hearing people were unable to get ahold of us for DV help.**
- It's not centered as it should be. It's more reactionary versus proactive - more about disability inclusion. When a client encounters a barrier, we may discuss it as a team and use it as a learning experience. That way, we can determine how to be more accommodating in the future - without the client having to advocate for those accommodations. As a leader in our organization, I'd like to see disability justice highlighted in our work. I recognize there is more we need to be doing.



Tojo Andrianarivo for [Disabled And Here](#)

- On occasion, staff push to have these conversations and to make changes that come up in them. We were able to move to a 32-hour work week for a couple months during the height of the pandemic and Black Lives Matter protests, in recognition of the emotional and mental toll on staff. There has also been recognition of how COVID has impacted people, in an attempt to give more space & time for people to take care of themselves.

(Continued on page 8)

What do you see as your agency's biggest challenge in infusing more disability justice concepts into your work? Themes include limited capacity, gaps in awareness and understanding of disability, leadership does not make it a priority, and biases.

- The focus on youth and wellness by mainstream LGBTQ folks especially around Pride events.
- **Realizing that people with disabilities like myself are making every effort not to feel and look disabled even when we are in pain or discomfort.**
- Disability justice can have a lot of different meanings to different people who all have a say in it and are all affected by it. Sometimes, reconciling where these ideas clash to have general guidelines is very difficult.
- Understanding that all the new technology can be difficult for those of us that are not used to it. I understand that it is easy for those that are used to it, but it is a lot for those that have kept info on index cards or need to write it down.
- Education, awareness, and understanding for staff. **Not being afraid of the most marginalized (e.g., nonspeaking people, people who need help with activities of daily living).** Figuring out what it looks like to serve disabled people accessibly without being a disability-specific organization.

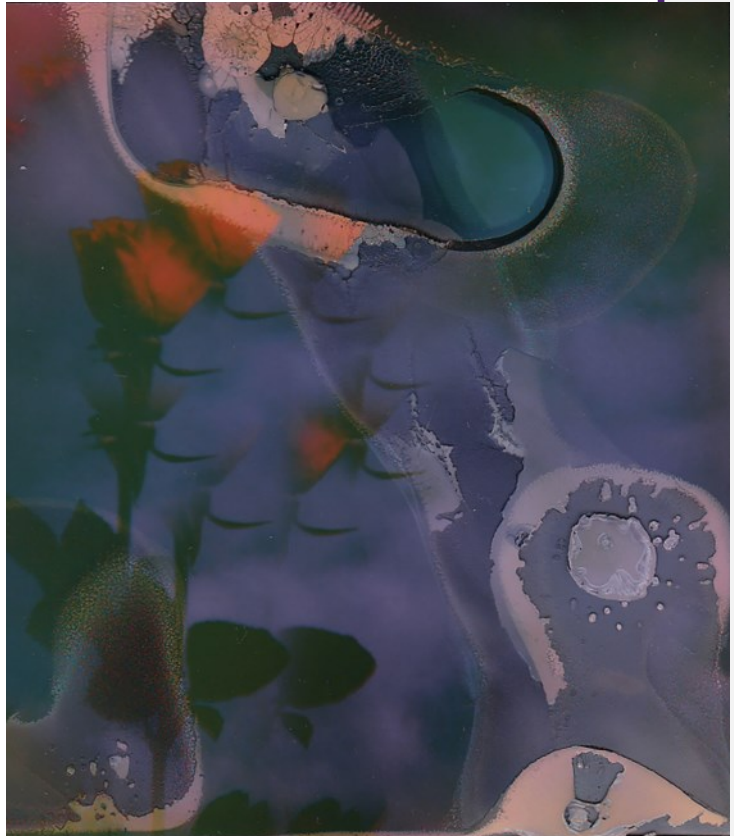
Below, and in white text boxes on the following pages, are the stories people offered within our survey. We are grateful for your contributions, and for sharing a diversity of perspectives. Stories have been edited for clarity and brevity.

I was a professional dancer and entertainer when I was younger. Because of three hip replacements and ten hip surgeries I used crutches, canes, and walkers from 2000-2005. These surgeries impacted my mobility as well as my mental health. I not only have to navigate my physical and mental disability, I have to navigate ableism and ageism which affect my life on a daily basis. Through the support of my family, friends, and Diverse & Resilient, I am able to better manage my feelings and emotions around my disability.

— Ronnie Grace, Diverse & Resilient

My sister struggled with mental illness for many years. Because of this she became a victim of extreme domestic violence. A man took advantage of her, controlled her, isolated her, and tortured her for a year, then shot her.

Miraculously she lived but was left partially paralyzed. She then faced life with her mental health disability and a physical disability. She felt like a burden to the family. She suffered daily nerve pain from the bullet fragments that could not be removed. She also struggled with the emotional damage from the man who shot her. After a year and half, she succumbed to these challenges and died by suicide.



She experienced so many injustices. She was

Photo by Lisa Fotios from [Pexels](#)

required to complete copious amounts of paperwork in order to get medical procedures covered by Medicare and the Victim's Fund. She couldn't keep up and we found all of it, along with the medical bills, in boxes. She struggled to get rides to the places she needed to go, and often had disrespectful drivers. There were so many injustices in the court case, I can't even begin to describe them.

— **Michelle Uetz, [Rocky Hill Parent Peer Specialists](#)**

When I think of the term “disability”, I internally bristle at the negative connotation that surrounds the word. I am Deaf, and the hearing society classifies my deafness as a disability. Historically, Deaf people have been perceived through a medical paradigm as having hearing “loss” or “disability” when it is actually the lack of equity that excludes us. There are countless barriers to communication and access to information for the Deaf community.

Within the Deaf community, we identify ourselves as members of a distinct linguistic and cultural group. It has been my experience that the hearing society views Deaf people as incapable or lacking the capacity to perform in various areas. It makes me feel that we are socially ostracized and continuously treated with disrespect.

Ableism is in every part of my everyday life, including my work with survivors. For example, when a Deaf person is alone, who do they go to for support and how do they acquire information? Most of the information, resources, services, and programs are available through spoken and written formats, primarily in the English language; a Deaf person may not know there are resources available, so ableism prevents them from seeking and obtaining support. There are limited opportunities to understand what's going on in their primary language, American Sign Language (ASL).

For example, video relay services (VRS) is a telecommunication service that allows individuals to communicate with an interpreter over video. Although VRS has improved telecommunication access for Deaf people, there can still be problems. When a Deaf person is trying to call an agency, the hearing receiver who is unfamiliar with VRS can be confused, impatient, and hang up or try to rush the caller. If the internet signal is weak, the VRS call may not go through, or the parties may experience frequent disconnections.

Hearing people can receive information within their reach while Deaf people simply cannot, as it takes twice the time and effort to obtain and understand information at a pace that allows for processing, pauses, rechecking, and verifying information.

Within my agency, [Lily of the Valley](#), and [Domestic Abuse Intervention Services](#) (DAIS), where I work, I’ve initiated and supported conversations with staff, constituents, and Deaf individuals.

Before a Deaf person meets with an agency for services, I ensure that the agency provides interpreters – if not, conversations need to ensue to arrange for accessibility. I help the Deaf person to process and articulate what they want to say. If the Deaf person is considering

(Continued on page 11)

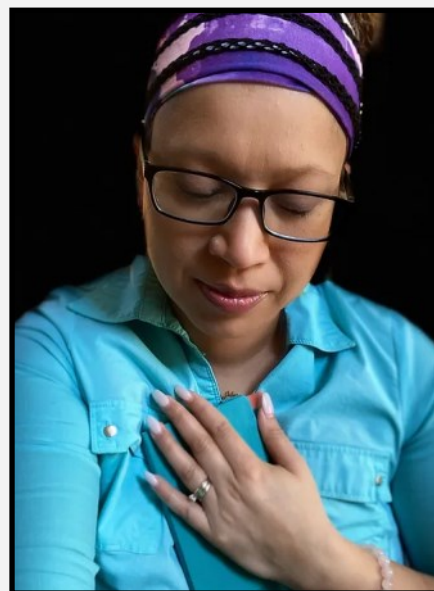
(Continued from page 10)

shelter, I explain services, benefits and challenges of staying at a shelter, e.g., being with other "hearing" residents – would the Deaf person feel isolated and want to return to the perpetrator? Or, if they decide to go to the police, will there be necessary accommodations? How can I support them?

DAIS collaborates with Disability Rights Wisconsin. When Deaf individuals assert their civil rights, I help them attain the support of a representative. We ensure ADA compliance regarding communication accessibility, interpreter qualifications, and ensuring that the representative has no personal or professional conflicts with the individual that will hinder their ability to do their job. I created an ASL request form to be more trauma-informed and efficient in communication. This kind of support often serves as a foundation for the Deaf person's empowerment in requesting additional community resources they need to stay safe and provide for themselves; it also continuously fosters learning about disability justice.

My agency's biggest challenge to disability justice is finding creative ways to provide consistent, equitable services that promote communication. Reading and signing documents, understanding terminology, and communicating with hearing colleagues is extremely challenging for Deaf individuals within the general workforce. I use ASL to explain difficult documents and procedures. I offer presentations about intersectionality, microaggressions, bias, and privilege. Because of my extensive experience providing services to Deaf individuals I am keenly aware of challenges my agency faces, and I work toward infusing disability justice concepts into our work.

— **Anabella Price, Lily of the Valley**



Ana Price presented two webinars in March, 2022. Below are descriptions and links to the recordings.

Deaf's Lens: Understanding Domestic Violence in the Deaf Community Recording

This presentation is for hearing advocates who would like to be more attuned to the experiences of domestic violence within the Deaf community.

I Have a Deaf Client—Now What? Recording

This presentation builds on the previous webinar, offering steps hearing advocates can take to be prepared in advance to respond compassionately, appropriately, and quickly to the needs of their Deaf clients.

I learned ASL as an older adult starting approximately 10 years ago. I learned from a friend who is deaf, and I really took to the language. Through this friend, I was immersed in Deaf culture, and spent a great deal of time in the Deaf community.

My friend and I attended the same church, and when our long-time certified interpreter and her husband relocated, I was asked to provide ASL interpretation during our weekly services, and to create and deliver ASL classes to several adoptive families of kids who were deaf or hard of hearing.

I have taught many friends sign language basics and have interpreted for places like a housing authority in northeast Wisconsin who needed someone to interpret in a rush and could not get an interpreter here from Milwaukee quickly enough to meet the need. In Fall of 2000, I was asked by an accredited homeschool in northern Wisconsin to design and teach beginner and intermediate ASL classes to its students from across the US. I continue to offer that service.

I have always wanted to become a certified interpreter, but there are many obstacles. One is that, according to my interpreter colleagues, there is only one school in Wisconsin, located in Milwaukee, where you can become a certified interpreter and it's a four-year program. It would be great if the certification process could be streamlined/accelerated and were more accessible. Going back to school full-time for me was not an option. I was not in a position to quit my job or to take on student debt. There were no evening or weekend certification programs or virtual option available, and I was not able to travel to Milwaukee daily for classes.

People have often told me that there is a shortage of ASL-certified interpreters in the state and having to wait for certified interpreters to become available and/or travel from southern Wisconsin resulted in a delay of services. I think that the certification process needs to be reimagined so that more people like myself can become certified interpreters for deaf and hard of hearing clients.

— **Tracey Robertson, *HELP of Door County***

I was born Deaf and I have experienced many communication access issues while growing up. For example, my mom had to fight for my right to have an ASL interpreter at school and at various appointments. I would also get left out of conversations many times, not knowing what's going on with my school friends or other people. These are just a few of so many things I've gone through while growing up.

— **Andrea Schneider, *Deaf Unity***

Disability justice requires addressing all other forms of systemic oppression. It requires ending the forced poverty that the United States imposes on disabled people in order to remain eligible for life-sustaining benefits. Disability justice requires completely reimagining our system of societal, communal support – to end means-testing, make services easier to access, stop requiring people to prove their needs, and recognize that we are all interdependent. Addressing financial constraints like the Social Security system will remove barriers for many disabled survivors who are tied to their abusers for economic reasons. The same is true for designing more affordable, accessible housing.

I do not believe disability justice is possible under capitalism. As long as the sale of a person's labor determines their worth to society, disabled people will experience discrimination. Accommodations cannot replace a truly accessible, truly universally designed environment. Things like attendance requirements and limited time off

disproportionately affect disabled people who may not be able to keep up with the pace expected by a post-industrial society where efficiency is the most valuable commodity.

I have chosen not to access necessary treatment for my disability because it would conflict with my employment. I have worked while in pain because I didn't have enough paid time off available to me, or because I had work commitments that I could not reschedule. I have sacrificed my physical and mental health in order to maintain employment, because I need employment to survive.

— **Emery Rankin Utevsky**



Chona Kasinger
for **Disabled And Here**

I was disabled for 6 years for a medical condition that required treatments 3 times a week. Trying to handle working a full-time job around those treatment was very difficult. After increased family stress (passing of my father, needing to move and be primary caregiver to my mom), I was no longer able to manage working full-time. After being on long-term disability from my employer for 3 years, they changed the health insurance coverage from the entire 5-year term of the disability to 3-years of coverage. I received notice that in 6 weeks I would not have health coverage. Also, the insurance company mistakenly overpaid me \$6,600 and only found the error by auditing my claim after it ran out. They demanded payment of the full amount in 24 months, and I had no resources to pay the money back. They actually overpaid me for 3 years. I was living on my social security disability income and paying \$550 in health insurance at the time. That created a major financial burden that I'm still attempting to payoff. I tried to get a lawyer to help me after finding a US Supreme Court ruling similar to my case in which the defendant won and did not have to pay back the money, but the way attorneys are legally compensated for disability cases, only an attorney working pro bono could take on my case.

— **Anonymous**

"I've noticed tons of abled activists will happily add "ableism" to the list of stuff they're against (you know, like that big sign in front of the club in my town that says "No racism, sexism, homophobia, transphobia, ableism") or throw around the word "disability justice" in the list of "justices" in their manifesto. But then nothing else changes: all their organizing is still run the exact same inaccessible way, with the ten-mile-long marches, workshops that urge people to "get out of your seats and move!" and lack of inclusion of any disabled issues or organizing strategies. And of course none of them think they're ableist."

— **Leah Lakshmi Piepzna-Samarasinha**

Care Work: Dreaming Disability Justice

Ableism can mean a place is inaccessible to people who have different kinds of disabilities, including physical limitations or people who are blind, deaf, or deaf-blind. A couple of times, agencies reached out to Deaf Unity to ask for help when a survivor with a disability needed assistance with things like rights under the ADA. I've seen many struggles with ADA, which should protect the most basic rights to access.

Even though we are advocates for Deaf survivors of domestic and sexual violence, some of the referrals that come to us are related to legal matters under ADA, such as completing the workforce discrimination form. AS DV/SA advocates, we are not legal advisors and don't have knowledge of the process of fighting workforce discrimination. We are willing to help it out, but we are not legal advisors.

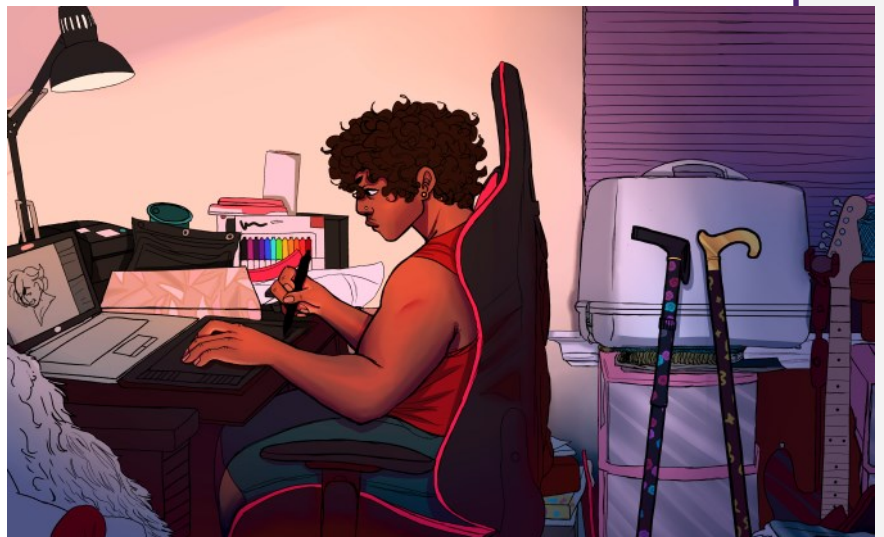
We are working on shifting the perspective of what people assume and what it really is.

What I see as our biggest challenge in infusing more disability justice concepts into our work is that disability plus means more than one disability: For example, a deaf person who has cerebral palsy may need accommodations that we don't know about. We need to ask the person who has more than one disability to make sure we provide the right accommodations. I don't want to focus only on that deaf person who needs language access that we know how to provide.

— **Anna Dorst, Deaf Unity**

People with disabilities often have more health information to keep private. Yet they are often asked more often to disclose it, such as to get accommodations. And when disclosing it, self-determination is disrespected because, if not seeking the "correct" treatment or a doctor does not order something, whatever's requested may not be approved. We need to believe people, and we need to respect their choices.

— **Anonymous**



Dice Bundy for Disabled And Here.

I deal with several mental health diagnoses. I have depression, anxiety, OCD tendencies, and ADHD. For the most part, I feel my workplace has been accommodating. I've gotten time off if I've needed to take time to focus on self-care and managing my symptoms. Other staff have been allowed to do the same.

Now that I am in a leadership role, I'm able to come into work later and stay later in the day (when I'm able to focus best).

However, there have been times where I feel that my passion and commitment have been questioned. I *know* that I have a fire in my heart for advocacy work – it's so important to me. It's upsetting to know that the quality of my work doesn't always speak louder than the quantity or time of day I work. Good workers are always seen as the people who work that 8 am-4pm shift. I might come in later, but some nights I can be here until 11pm.

I'm thankful that I have the flexibility to function in a way that works for me. It's harder to do this with staff who work with clients, though. I want to provide better accommodations across the board. I see and recognize the work my neurodivergent coworkers put in. I also recognize that this is one small piece of the puzzle, and I need to do a lot more advocating for other accommodations as well. I want to know how to change the culture.

— ***Anonymous***

I have Multiple Sclerosis and Sjogrens, both of which are often invisible.

— ***Kathy Flores, Diverse & Resilient***

Invisible Disabilities Defined

An “invisible,” “non-visible,” “hidden,” “non-apparent,” or “unseen” disability is any physical, mental, or emotional impairment that goes largely unnoticed. An invisible disability can include, but is not limited to: cognitive impairment and brain injury; the autism spectrum; chronic illnesses like multiple sclerosis, chronic fatigue, chronic pain, and fibromyalgia; d/Deaf and/or hard of hearing; blindness and/or low vision; anxiety, depression, PTSD, and many more. We understand the body as always changing, so disability and chronic illness may be unstable or periodic throughout one's life.

— Taken from the **Invisible Disabilities Project**

My wife is semi-disabled due to back related problems. Because sometimes she can get around without aids, people have a hard time accepting that she has a handicap license to be able to park closer to the entrance of facilities. And although the majority of individuals are respectful enough – holding doors, being aware she is in a mobility chair – many people still seem to pay absolutely no attention and have let doors close in her face and almost run into her with shopping carts.

— **Anonymous**

I haven't often considered myself to be living with a disability...I live with obsessive-compulsive disorder (OCD) and obsessive-compulsive personality disorder (OCPD) and the work I do tends to be very detail oriented. I'm constantly monitoring my work to prioritize people and relationships over the structures of the work, which is something that involves close, frequent attention to my disability.

— **Anonymous**



Dominique Davis for **Disabled And Here.**

Spotlight on Nancy Yang

After a recent conversation about what disability justice (DJ) looks like in Wisconsin, Ellie Jarvie of Disability Rights Wisconsin e-introduced me to Nancy Yang. We wanted to spotlight people who are doing DJ work in different parts of the state. Nancy and I spoke over Zoom about the ways their roots in DJ have been manifested in their work and studies. Below and on the following pages are my questions and Nancy's responses.

— Colleen Cox

How did you enter into disability justice (DJ) work?

I grew into disability justice work the same way that many disabled folks do: through becoming disabled. I experienced altered states for the first time when I was twenty years old, and I was institutionalized many times for my madness over the course of four years. It was a strange time trying to make sense of everything that was happening to me, and it was through learning about ableism and sanism that I reclaimed power over my experiences and a renewed passion for justice.

In the beginning of that learning, I was still very isolated as a result of my psychiatric trauma, and I consequently

(Continued on page 19)



Nancy Yang (they/them or nws/lawv) is an advocate with expertise and research experience on topics of ableism, sanism, and disability justice both in and out of the Hmong community.

As a mad neurodivergent queer and nonbinary Hmong psych survivor, Nancy has been radicalized both by personal lived experience and engagement in social justice movements. They believe in undoing the harm of carceral systems through abolition, transformative justice, queer justice, racial justice, and disability justice. Nancy's work is always within community-building, with intersectionality, cross-movement solidarity, interdependence, and leadership of the most impacted.

Nancy has a degree in Geography from UW - La Crosse and is completing a Master of Arts program in Disability Studies at the City University of New York School of Professional Studies.

focused a lot of my energies on academia and research. I found my way to disability studies. As one of my mentors used to say, “research is me-search”, and disability studies was the perfect situation for me-search by a research-driven disabled person who just really needed community.

Over the course of my time in disability studies, I learned about disability justice as a theory and practice that is vastly different from academia’s approach to social justice. I found community with other multiply-marginalized disabled folks who care about disability justice, and I have been on that path towards healing and liberation ever since.

In our work to prevent and end abuse, we recognize that all forms of oppression are linked. What are some examples of how your DJ work has been informed by the realities of abusive or harmful behavior in interpersonal relationships?

Just as all forms of oppression are linked, our justice movements are also linked. I think of disability justice as a practice that goes hand-in-hand with transformative justice. So, when I think of DJ work with the harm that happens in interpersonal relationships, I think of what it means to reject disposability politics and create a culture of care and transformation that starts with how we treat each other.

Of course, I’m not perfect in how I do that in my own life. I definitely don’t have all the answers, and I don’t always reject disposability. I think we have to be okay with the messiness, the awkwardness, the hurt that goes along with trying to transform how our relationships look.

That said, when I think of examples I think of the people and institutions in my life whose actions didn’t match up with their stated values. The harm that comes from actions and values that are misaligned is difficult to handle—personally, when I know someone’s stated values that usually means I have already come to care about them. The insidious part of that is that the harm is even more hurtful. My DJ advocacy is based on how I want to eradicate abuse and minimize harm. And that desire is informed by the abuse and harm I’ve experienced first-hand.

When I think of disability justice with the harm that happens in interpersonal relationships, I think of what it means to reject disposability politics and create a culture of care and transformation that starts with how we treat each other.

(Continued from page 19)

Could you choose one of the 10 principles of DJ that resonates for you today? Which one, and what brings it to mind?

It's hard to pick just one, because I think all ten relate and feed into one another. Intersectionality tells us that it is important to recognize each other's Wholeness, Recognizing Wholeness is essential in our care for each other in Interdependence, Interdependence is a practice that brings our Collective Liberation, our Collective Liberation can only happen if we have Cross-Movement Solidarity and Cross-Disability Solidarity...I could go on. If I had to pick one, I'd say Interdependence, for the way that all ten principles rely on one another to create disability justice.

INTERDEPENDENCE

We meet each others' needs as we build toward liberation, knowing that state solutions inevitably extend into further control over lives.

– One of the 10 Principle of Disability Justice as articulated by Patty Berne and Sins Invalid

You have been immersed in DJ movement work within Hmong communities for some time. Where have you found spaces of greatest possibility for DJ as part of Hmong community? What have been some specific challenges for Hmong people with disabilities?

I wish it wasn't this way, but I think the spaces of greatest possibility for DJ in the Hmong community has been when disabled Hmong folks have been harmed. Even and especially within designated Hmong advocacy and Hmong disability spaces. It's when harm happens that I see harmed disabled Hmong folks looking for answers and landing on DJ.

I'm hopeful when I see disabled Hmong folks learning about and seeking DJ resources on their own, because when they can do that for themselves, there is more opportunity for leadership of the most impacted which recognizes disabled Hmong folks' wholeness. Designated Hmong advocacy and disability spaces don't do that for disabled Hmong folks.

(Continued on page 21)

People in rural environments experience barriers to access in many ways that urban dwellers do not (transportation, isolation, fewer options for employment, etc.). What might DJ look like in rural Wisconsin?

This is something that I think about as part of the La Crosse Disability Justice Collective. DJ feels so small and unheard of in rural Wisconsin, especially amidst so many local disability organizations that are led by non-disabled parents and professionals.

However, even when their values are not 100% aligned to DJ, we can't deny that local disability organizations are valuable resources. Without them, the disability community in rural Wisconsin would be much more isolated from each other than it already is. So I think one way we can expand DJ in rural Wisconsin is to build collaboration and bring education on DJ for and with existing local disability organizations and the disability communities within them.

I imagine DJ in rural Wisconsin as a creation of relationships which strengthen disability identity, empowerment, and community. And using whatever connections we have with one another to build that will be a huge component of creating DJ here.



Dice Bundy for Disabled And Here.

What is one thing that brings you joy in your everyday life?

My local coffee shops. My entire work and school life is remote, and these coffee shops have been the only place I get a glimpse of in-person community. I enjoy doing my work there because I thrive on body doubling (when two or more people are in the same space doing things separately, which can be helpful for productivity). I also just find my local coffee shops to be spaces of comfort. A couple hours writing or reading a book in my favorite coffee shop with a salted caramel oat milk latte makes me happy.

Book Group Discussion About — Care Work: Dreaming Disability Justice — By Leah Lakshmi Piepzna-Samarasinha

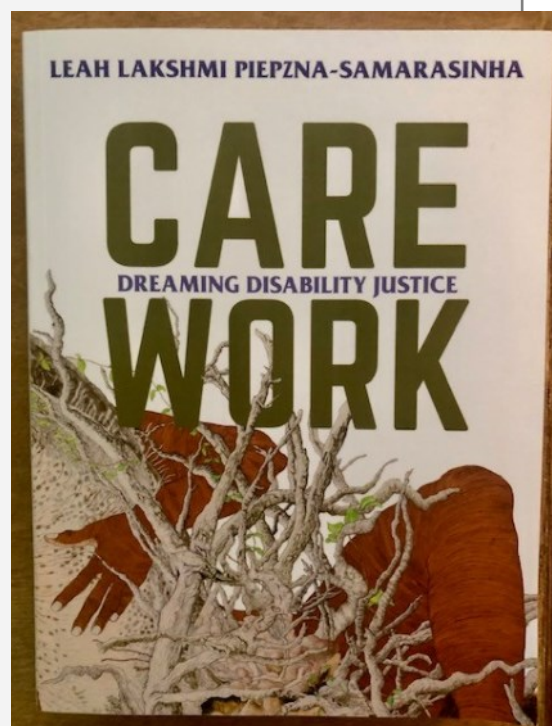
A Conversation with Jill Gonzales, Lydia Hartlaub, Ellie Jarvie, Kate Knowlton Pam Malin, and Elvita Erdmann (Disability Rights Wisconsin Victim Advocacy Program) and Colleen Cox (End Domestic Abuse Wisconsin)

After reading Care Work: Dreaming Disability Justice, by Leah Lakshmi Piepzna-Samarasinha, a group of us had a lively discussion via video call, facilitated by Lydia Hartlaub. I highly recommend reading this entire book of essays. However, if that's not doable for you right now, a summary is available:

Radical in Progress describes themselves as a one-stop shop for social justice study guides, whose main goal is to equip aspiring activists with the vocabulary, knowledge, and strategies they need to radically reimagine the future. Here are links to [Care Work: Dreaming Disability Justice Study Guide Part One](#) and [Part Two](#), from [Radical in Progress](#). (Also listed in resources, page 35.)

Below is a transcript of our November 28 book club discussion that has been significantly shortened and edited for clarity, with related links and quotes from the book.

— Colleen Cox



Lydia: I guess I'll just start by asking what did people think? What jumped out to people about the book?

Kate: I'll open with a frustration I have as an attorney. The total lack of enforceability for victims' rights, is just so frustrating, so defeating and disheartening. So, it's been unbelievably refreshing to feel supported in this program at Disability Rights Wisconsin (DRW). It's also been super eye opening because I am extraordinarily privileged.

(Continued on page 23)

Kate: I love the care web concept.

Jill: She talks about the collective care that it takes as a community. Historically, our ancestors really took care of each other. There wasn't a state system to do that. So...[in community] people want to be there to help you. But she said it took her about 10 years to be able to ask for and receive help. Because, let's face it, we are asking someone to be there in our rawest moments. So...it's so much easier to help people than to ask for help.

Colleen: A few things that stood out to me: Emotional care work and drawing attention to femmes, particularly working-class femmes often taking on that burden – how that work is not recognized, gendered and devalued. And the assumption that people with those kinds of identities will take it on...and it burns them out.

Also, the “**Ugly Laws**” [laws in some U.S. states from the mid-1700s to the 1970s, prohibiting people with certain disabilities from being in public spaces] and saying that what's really happening is “disappearing people” with disabilities, making them cease to exist.

Ellie: This book was so powerful; it evoked a lot of emotions, sadness that I'm not connected to the broader disability community in ways that I used to be. I used to do a lot, be a lot more connected across disability, especially in my early 20s...it was my first entrance into cross-identity connection, the recognition that we all have that common oppression. Whether we had a physical disability, whether we were deaf, blind or you know, myself, having Tourette...the disabilities might be different, but the common experience and the ways that we could help each other were the same. **I think particularly the essays about how making space accessible is an act of love in our communities, really spoke to a lot of the issues.** And cross-disability accessibility [in ways that] that people might not see as

(Continued on page 24)

Care webs break from the model of paid attendant care as the only way to access disability support. Resisting the model of charity and gratitude, they are controlled by the needs and desires of the disabled people running them.

We all deserve love. Love as an action verb. Love in full inclusion, in centrality, in not being forgotten. Being loved for our disabilities, our weirdness, not despite them. Love in action is when we strategize to create cross-disability access spaces. When we refuse to abandon each other. When we, as disabled people, fight for the access needs of sibling crips.

part of accessibility, like scent-free spaces. When she was talking about the folks in Toronto who would not go to events when they weren't accessible. I think, I haven't made those choices in my own life: I'm in a house that's not accessible. What does that mean for who can come in? I choose to go places that aren't accessible. How does that affect my connections differently?

So, I'm wrestling with a lot of it. Some of the other essays that that I really appreciated...the one on emotional intelligence really resonated with me. There is something about connecting with somebody who has similar peer experience, just having that lived experience and making that connection, there's a way that that permeates your life in a way that just reading about it can't.

And then I think the other essay that that's really relevant is ***Not Over It, Not Fixed, and Living a Life Worth Living: Towards an Anti-Ableist Vision of Survivorhood***. That one was powerful – the ways that abuse stay with us throughout our lives, that we can't expect to be healed, and different ways we can continue to show up because of what we've experienced.

Jill: Colleen, you talked about the **Ugly Laws - those laws plus our state system...we have the state money, we don't want to see these people on the street, let's institutionalize them. And this has everything to do with protection and advocacy work.** When I'm working in schools, you know the education for all handicapped children back in 1978 or 75, that was the birth of the idea.

Mainstream ideas of “healing” deeply believe in ableist ideas that you’re either sick or well, fixed or broken, and that nobody would want to be in a disabled or sick or mad bodymind.

Unsurprisingly and unfortunately, these ableist ideas often carry over into healing spaces that call themselves “alternative” or “liberatory.” The healing may be acupuncture and herbs, not pills and surgery, but assumptions in both places abound that disabled and sick folks are sad people longing to be “normal,” that cure is always the goal, and that disabled people are objects who have no knowledge of our bodies.

The Ugly Laws were interwoven with a mass creation in the 1800s and onward of hospitals, “homes,” “sanitoriums,” and “charitable institutions” where it was the norm for disabled, sick, mad, and Deaf people to be sequestered from able-bodied “normal society.

And in schools, it is about inclusion, and we had this whole de-institutionalization movement – keeping people in their homes and communities because that's where they're gonna get the support. Why let them waste away and spend way more money than if we could help them within their own communities and homes.

Ellie: She does lay out some of the history well, and one of the things too is she critiques, you know she talks about the nonprofit industrial complex, and protection and advocacy agencies and independent living centers. I mean, those were a direct response to political action by **ADAPT** and other groups in conjunction with the Black Panthers, that was supposed to be so radical.

Elvita: For me, this was very different. **I work mostly with the Hispanic community and my clients have a hard time saying they have a disability. My community is like, “no, no, no, I'm fine, I'm fine.”** No, you're not fine – for example, I have a client who has lupus, who continued to say, I'm fine, I don't need medical help. I don't need that. And I see how hard it is for her to travel even to work couple hours.

But also, I see that the community has a sense of we all get together, we pull it together. But I still I see in many places where there's no interpreter, no translator. You know what I mean? It's almost like saying, let's go stand up when you're in a wheelchair. And then there's documentation: if you have a disability, you're a woman of color and you're undocumented, none of the services would be available for them.

So, for me it was still hard because I see that she talks about language, I remember I had to read one part again because she talks about interpreters, but she meant ASL interpreters. I see people that have a hard time walking, and they have to walk farther because there's no signs to tell you the bathroom is to the left or to the right and they don't understand. So, I struggled with that part because that's very real to me in the Hispanic community.

A rights framework says that the ADA and other pieces of civil rights legislation give disabled “citizens” our rights: we simply state the law and get our needs met. Disability justice says: What if you're disabled and undocumented? What if you think the settler colonial nation we live in is a farce and a hallucination? What if you don't have money to sue an inaccessible business? What if the people giving you accommodations and access technology—or not—are not paid for by the state but part of your community?

Colleen: I was thinking about transformative justice. People who do harm have also got histories of victimization. And, thinking about being in community, relying on community to confront, you know, to really hold both the victimizer and the person who's been victimized...and how nobody's disposable, that is central to the idea of disability justice. It's very messy.

Ellie: Yes, it is. I was really struck when you said that piece about community, where no one gets left behind. One of the things I'm struggling with in my own Tourette community is people who have been abusive and have big names as peers in the community, how to reconcile that. I was ostracized from the community as young woman when I brought that up. And who gets in and who gets out? **It still has a lot to do with those old systems of power, no matter what we're dreaming for. The idea that even the most noxious person is deserving of care in our systems. In these informal webs, how do we make that happen?** There is a lot to wrestle with in those ideas.

Pam: When we say community – coming together as a community – there's a history of people with disabilities that when they're different or “less than” they get taken out of the community and put into an institution, which is a lot of what we continue to work on.

Greatly simplified, when you're in an institution, nobody sees the abuse. When you're in community, you have people who care whether or not you show up to work or whether you went to church this week, you have people who check up on you and that's community. Not community because of a disability - that's just community. Statistically, abuse happens less when people are part of a community. So that whole piece of inclusivity really isn't just about wanting to be included, it's wanting to be safer...

People's fear of accessing care didn't come out of nowhere. It came out of generations and centuries where needed care meant being locked up, losing your human and civil rights, and being subject to abuse.

The care work we give is essential to building movements that are accessible and sustainable. We are building and maintaining movements when we're texting to make sure someone is okay, talk on the phone for hours, talk shit on the couch, drop off a little care. Those things are not a sideline or an afterthought to our movements. They are our movements.

(Continued from page 26)

We all know of situations where [paid] caregivers go into homes, but don't lift a finger while they're there. Or they abuse people, take their money or take advantage of them in some way. And I mean, I think all of us could probably think of a situation we know about where the person has to choose: Do I turn this caregiver in for what they've done and then have nobody, or do I put up with them taking my debit card and taking money out of my account? But I can't prove it because I had to give them my pin number because I can't key it in myself. So, when they put it back in my wallet the next day and I'm missing money, do I turn them in and then have nobody?

Ellie: And that's only been made worse by COVID. In these last couple years, people's choices as Pam said are more limited. So now we even have to say, if I get rid of this person who is inappropriate or abusive, who else will I get? Will they be worse? When will I even get somebody? When you have an immediate physical care need that's no small thing.

Pam: And it's acceptable to just look the other way for certain classes of people.

Ellie: Yeah, especially when somebody has a mental health disability—just because somebody has a mental health issue doesn't mean they aren't also experiencing abuse, neglect. Being a victim of crime, both can be true.

Colleen: I was completely unaware of this story (referenced in the book) of [Jerika Bolen](#) in Appleton. I don't even know what to say. That just was shocking to me.

Lydia: It made me think of movies like [Me Before You](#). It's a love story [between a man and a woman] and he is paralyzed from the neck down. I didn't see the movie, I know what happens because I looked it up. The plot seems just kind of...it felt ablest...like life with a disability was worth living but kind of romanticized in a way that made me uncomfortable.

Kate: [\[Jerika Bolen's suicide\] was just in 2016, by the way. This isn't like ancient history. This is very recently we said her life can't be that worth it.](#)

Our focus is less on civil rights legislation as the only solution to ableism and more on a vision of liberation that understands that the state was built on racist, colonialist ableism and will not save us, because it was created to kill us.

Spotlight on Dr Sami Schalk

Dr. Sami Schalk is an Assistant Professor of Gender & Women's Studies at University of Wisconsin-Madison, where her research focuses on disability, race, and gender in contemporary American literature and culture. Much of her extensive body of work is academic, more disability theory than disability justice. However, you will also find mainstream and popular writing on the [Dr. Sami Schalk website](#), where in keeping with her belief in open access, Schalk offers many selections as links or free downloads. Our work to end violence is illuminated by the concepts shared in much of her writing. Highlighted below short summaries and links to Schalk's books, and to a 2021 article, *Reclaiming the Radical Politics of Self-Care: A Crip-of-Color Critique*.



Dr. Sami Schalk (photo by Sam Waldron) from <https://samischalk.com/cv/>

Bodyminds Reimagined – I came across Schalk's fascinating interpretation of the 2016 film, *The Girl with All the Gifts* (pages 11-17 in the introduction of *Bodyminds Reimagined*, available for free download) a few years ago. In this discussion, Schalk draws upon the film as a "useful popular culture example which demonstrates the utility of [her] key terms, bodymind and (dis)ability, and [her] primary theoretical frameworks, intersectionality and crip theory, in interpreting (dis)ability, race, and gender in nonrealist representations." Viewing the film was a much richer experience coupled with reading Schalk's interpretation.

Black Disability Politics

Dr. Schalk's most recently published book, ***Black Disability Politics***, looks at how disability has been important to Black activism for many years, and reasons why Black disability work may not have been recognized. Research for the book included history of the Black Panthers and the

(Continued on page 29)

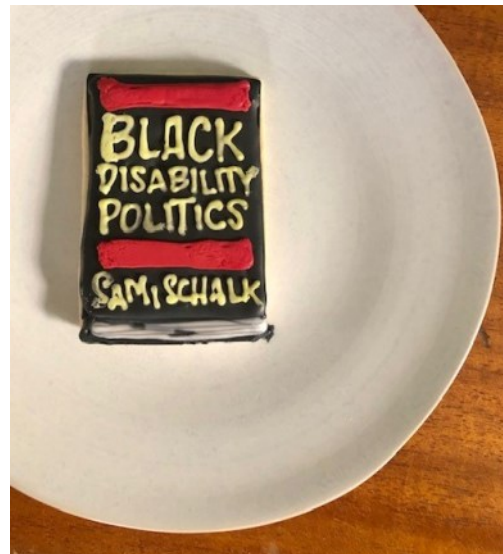
(Continued from page 28)

National Black Women's Health Project, as well as interviews with individuals currently doing Black disability work. Outlining how disability is profoundly connected to race and racism, the book argues that disability justice is essential to Black liberation. Black Liberation Politics is an open access book and free PDFs of each chapter can be downloaded at [Dr. Sami Schalk's website](#).

Reclaiming the Radical Politics of Self-Care: A Crip-of-Color Critique,

by Jina B. Kim and Sami Schalk, discusses the emergence of self-care as a popular topic in mainstream media, something that we all must find ways to do. As discussion of self-care

has proliferated online, a powerful quote of Audre Lorde has become familiar to many of us: "Caring for myself is not self-indulgence, it is self-preservation, and that is an act of political warfare." Schalk and Kim examine the deeper context of that quote as it appeared in Lorde's **A Burst of Light**, and more broadly, in the life circumstances of Audre Lorde as a politically outspoken Black lesbian and author who was living with cancer at the time it was written. As the title of the article makes clear, the authors "reclaim" care for ourselves and each other as political, centering those who are most marginalized and harmed within existing white supremacist, capitalist structures. As advocates and activists for survivors of violence, we have long understood that self-care is critical for showing up to do the work effectively, with compassion. This article offers a more profound understanding of what self-care and care could mean.



*A cookie from a November 2022 book signing at **A Room of One's Own** in Madison*

— Colleen Cox

Elder Abuse and the Intersection of Aging and Disability

Elder abuse has always been a critical issue for communities to address because of the greater vulnerability of older adults. It's becoming increasingly important for us to be talking about elder abuse at this time because as the population of older adults is growing, the prevalence of elder abuse will grow as well.

In 2020, there were 55.7 million Americans age 65 and older, representing 17% of the U.S. population—more than 1 in every 6 Americans. ([2021 Profile of Older Americans](#)). Older adults are projected to outnumber children under age 18 for the first time in U.S. history by 2034, according to US Census Bureau projections ([By 2030 All Baby Boomers Will Be Age 65 or Older](#)), and by 2060, the population of adults 65+ and is projected to reach 94.7 million.



Photo by Barbara Olsen from [Pexels](#)

A CDC report found that approximately 2 in 5 adults age 65 or older are living with a disability ([Prevalence of Disabilities and Health Care Access by Disability Status and Type Among Adults — United States, 2016](#)). Some older adults are *aging into disability*—as they age, they develop new physical or mental impairments. Others are *aging with a disability*—they age with an early-acquired disability. Due to medical and technological advances, the average age of people living with early-acquired physical disabilities is increasing ([Growing Older with a Physical Disability: A Special Application of the Successful Aging Paradigm](#)).

Elder abuse is more prevalent than our society's narrative might lead us to believe. One study showed that 1 in 10 community-residing older adults reported abuse. ([Prevalence and correlates of emotional, physical, sexual, and financial abuse and potential neglect in the](#)

(Continued on page 31)

United States: The National Elder Mistreatment Study).

Bear in mind this is a study that counted people who were able to be reached over the phone and who self-identified abuse or financial exploitation. It didn't account for older adults who didn't have a phone, who didn't answer the phone, or those with cognitive capacity issues preventing them from answering the question. It also didn't account for those living in an assisted living or other facility. So, while this is a staggering number it's likely a low estimate. Older adults with disabilities face an even greater risk of serious violent crime and other forms of abuse than their counterparts. In fact, abuse and violence against people with disabilities occurs at rates two to three times that of the general public. ([Epidemic Rates of Violence](#)).

Ageist and ableist stereotypes of older adults compound their risk for harm. Older adults and adults with disabilities are often perceived by society as helpless and dependent.

Ageism and ableism diminish how older adults are valued and create a culture where the abuse, neglect and exploitation of older adults is tolerated, minimized, or ignored.

Too often older adults are not believed when they report abuse because of assumptions about their cognitive ability, and/or misconceptions about the dynamics of interpersonal violence, sexual assault, and stalking. Many assume older adults have dementia and don't understand – or can't report – what is happening to them. They may view older adults as less worthy of respect or dignity if they have physical limitations or rely on others for care. Instead of seeing elders in the fullness of their life experience, such attitudes lead us to viewing older adults as disposable, inconvenient, and irrelevant.

Without addressing ageism and ableism in ourselves, our programs and our system responses, older adults who experience abuse and those who harm them will continue to go unnoticed.

— Sara Mayer

We need to ask ourselves, what are the conditions that will allow disabled QTBIPOC elderhood to flourish? For me, some of those conditions are creating accessible community spaces.

– Leah Lakshmi Piepzna-Samarasinha, in *Care Work: Dreaming Disability Justice*

Guardianships

Guardianship is a legal process by which someone – a guardian – is given the authority to make decisions on behalf of another person – a ward – due to the ward’s infancy, incapacity, or disability. The guardian is required to act in the ward’s best interest. Among older adults, guardianship can be appropriate when an individual no longer has the capacity to make or communicate responsible decisions due to mental illness, physical illness or disability, dementia, or other causes. Once appointed by a court (and guardianships can only be established by court order), the guardian possesses the same powers, rights, and duties as a parent to a child – they can determine where the ward will live, what personal property they may own, where and how they will receive medical treatment, and how their finances are managed.

In the context of elder abuse, a well-intentioned guardian can protect an incapacitated victim from future harm and can pursue abuser accountability on the victim’s behalf. However, it can not be stressed strongly enough that establishing legal incapacity and placing an individual under guardianship is a serious deprivation of autonomy that can be difficult to reverse. It grants a huge amount of power to the guardian, which, in the wrong hands, can be a means to exert power and control. While safety measures – such as annual reviews by the court – exist, they can be hard to monitor and enforce.

Once a person no longer has the legal right to state concerns or protest a decision made on their behalf, the erosion of their personhood has begun.

– *Rethinking Guardianship to Protect Disabled People’s Reproductive Rights*

The guardianship system can be manipulated and used to exploit and abuse older adults. Fortunately, many states are taking steps to review and update their guardianship laws, mostly with an eye to safeguarding rights; detecting, addressing, and preventing abuse; and preserving autonomy where possible. We encourage you to review your state’s guardianship statutes; learn more about how guardianship can be used to harm, not protect, older adults.

For more about guardianships, see the American Bar Association Commission on Law and Aging’s page of resources on guardianship and supported decision-making and visit the National Center on Law and Elder Rights’ resources on guardianship and elder abuse — including issue briefs, checklists, and recorded webcasts — part of their Elder Justice Toolkit.

— Ann Laatsch, J.D.



Spotlight on T. S. Banks

The Arts + Literature Laboratory, where T.S. Banks performs on January 21, 2023, describes T. S. Banks (he/him) as a Black & QTDisabled, non-binary teaching artist, poet, and playwright and Founder of **Loud 'N UnChained Theater Co.**

His work addresses visioning for Black Liberation, a critique of the medical system, radical care + access, madness, QT Liberation, disability justice, & abolition. T's chapbooks "Call Me ill" , "Left" & "SPLIT" can all be found on **his website**.

Photo, above, and Bio, below, from T.S. Banks's website:

<https://tsbanks87.wixsite.com/tsbanks>

T Banks 29, from Madison, WI is a community organizer, a mental wellness advocate, poet and playwright. After graduating with a degree in English Creative Writing from UW-Madison, Banks has successfully used his art through plays and poetry to address Racism, Transphobia, and Ableism. As a Black Trans, Queer person with a disability, T believes the movement for Black Lives must be intersectional and deeply connected to the struggle to end Patriarchy, specifically as it manifest as violence against Black Trans folks. His work addresses the need for the Black liberation movement to be accessible to those with mental wellness challenges and or physical disabilities as well fight for the ability of these populations to regain their autonomy in a capitalistic society.

DISABILITY JUSTICE RESOURCES

This list of resources has largely been culled from the wealth of disability justice knowledge accessible online. We included links to each one and grouped them into seven categories. Videos and podcasts list the recording length. Books and toolkits are accompanied by descriptions. We note where a resource is discussed elsewhere in the publication.

Articles and Blog Posts

[Black Autistics Exist – an Argument for Intersectional Disability Justice](#) (by ChrisTiana ObeySumner, Seattle Times, December 2018)

[Destigmatizing Disability](#) (Blog post by NCALL Staff, July 2021)

[“Disability Justice” is Simply Another Term for Love](#) (Blog post by Mia Mingus, Leaving Evidence, November 2018)

[Disability Justice and Elder Activism: Two Sides of the Same Coin](#) (By Sarah Kim, Next Avenue, November 2022)

[Disability Often Intersects With Domestic Violence. Here’s How to Better Help Survivors](#) (By Angela Kim, Yes Magazine, July 2022)

[How long covid could change the way we think about disability](#) (By Frances Stead Sellers, The Washington Post, June 2022)

[Reclaiming the Radical Politics of Self-Care: A Crip-of-Color Critique](#) (Jina B. Kim and Sami Schalk, 2021. Found on this comprehensive listing of articles on Dr. Schalk’s website: <https://samischalk.com/articles/>)



Photo by Marcus Aurelius from [Pexels](#)

(Continued on page 35)

Books

Black Disability Politics by Sami Schalk (2022)

See Spotlight of Dr. Sami Schalk, page 28, for the description.

Care Work: Dreaming Disability Justice

by Leah Lakshmi Piepzna-Samarasinha (2018)

In this book Piepzna-Samarasinha discusses how predominantly sick and disabled Black and brown queer people have created ways for sick and disabled people to receive support and care through their autonomy without relying on the state or their biological families. (See page 22 for a book club discussion.)

A *Care Work: Dreaming Disability Justice* study guide is available from [Radical in Progress](#), who aim to equip aspiring activists with the vocabulary, knowledge, and strategies they need to radically reimagine the future. Link to the study guides: [Care Work: Dreaming Disability Justice Study Guide Part One](#) and [Part Two](#)

Crip Kinship: The Disability Justice & Art Activism of Sins Invalid

by Shayda Kafai (2021)

Crip Kinship explores the art activism of Sins Invalid, a San Francisco Bay Area-based performance project, and its radical imaginings of what disabled, queer, trans, and gender-nonconforming bodyminds of color can do: how they can rewrite oppression, and how they can gift us with transformational lessons for our collective survival.

Disability Visibility by Alice Wong (2020)

Disability Visibility is a compilation of original essays by people with disabilities. There are too few stories about what it's like to be a disabled person navigating environments designed for the nondisabled. This collection brings visibility to some of these diverse experiences and shows how limiting our ideas about disability really are. Link to a [plain language summary](#) of the book, as well as a [Discussion Guide](#) by Naomi Ortiz.

Link to a [Disability Visibility book report](#) by Rachel Spencer, a deaf writer who graduated from Weber State University with a Bachelor's degree in Creative Writing and a minor in Anthropology. It is found her website, [Listen Up: A place for writers and educators to learn about disabilities](#).

(Continued from page 35)

The Body is not an Apology by Sonya Renee Taylor (2018)

Humans are a varied and divergent bunch with all manner of beliefs, morals, and bodies. Systems of oppression thrive off our inability to make peace with difference and injure the relationship we have with our own bodies. *The Body Is Not an Apology* offers radical self-love as the balm to heal the wounds inflicted by these violent systems. In **Your Body Is Not an Apology Workbook**, author, activist, and poet Sonya Renee Taylor invites us to reconnect with the radical origins of our minds and bodies and celebrate our collective, enduring strength. As we awaken to our own indoctrinated body shame, we feel inspired to awaken others and to interrupt the systems that perpetuate body shame and oppression against all bodies.

The Future is Disabled: Prophecies, Love Notes and Mourning Songs by Leah Lakshmi Piepzna-Samarasinha (2022)

In *The Future Is Disabled*, Leah Lakshmi Piepzna-Samarasinha asks some provocative questions: What if, in the near future, the majority of people will be disabled - and what if that's not a bad thing? What if disability justice and disabled wisdom are crucial to creating a future in which it's possible to survive fascism, climate change, and pandemics and bring about liberation?



*Photo by Cottonbro Studios
from **Pexels***

Year of the Tiger: An Activist's Life by Alice Wong (2022)

Described by the book's publisher as "a groundbreaking memoir in essays offers a glimpse into an activist's journey to finding and cultivating community and the continued fight for disability justice." A plain language summary of the book (and a description of the importance of plain language summaries) can be found [here](#). Wong's friend and fellow disability justice organizer, Sandy Ho, offers a [discussion guide](#) to accompany the memoir.

(Continued on page 37)

(Continued from page 36)

End Abuse Recorded Webinars that highlight the intersections of disability and Deafness with domestic abuse:

[Deaf's Lens: Understanding Domestic Violence in the Deaf Community](#) and [I Have a Deaf Client—Now What?](#), presented by Ana Price are described on [page 10](#).

[Brain Injury and Intimate Partner Violence 101](#)

Kathy Connolly and Michelle Ruhl-Ortiz from Harbor House discussed traumatic brain injury among survivors of domestic abuse – a common but often overlooked injury that can be mistaken for PTSD or mental health issues – including practical tips on how to ask the right questions, make accommodations, and know when to make referrals so we are meeting survivors' crucial needs. (April 2022)

Podcasts of NPR's [On Point](#) and [The Takeaway](#) that aired early in 2022 focused on brain injury as an invisible epidemic among survivors of domestic violence. You can find additional resources on their websites.

Podcasts

[Disability Visibility](#) (Podcast Series hosted by Alice Wong)

[Possibilities Podcast S3 E7: Possibilities of Care Futures with Leah Lakshmi Piepzna-Samarasinha](#) (1 hr. 4 min. | November 2022)

[Imagine Otherwise by Ideas on Fire: Leah Lakshmi Piepzna-Samarasinha on Disability Justice](#) (31 min. 44 sec. | May 2018)

[From What If to What Next: 63 – What if disability justice, deep inclusion, and liberation were centered in healthcare, education and the arts?](#) (51 min. 31 sec. | November 2022)

[abolition is for everybody: Abolition is Disability Justice](#) (59 min. | September 2021)

[PreventConnect: Disability Justice and Primary Prevention Part 1 | Moving at the Speed of Trust](#) (47 minutes | November 2022)

[It's Been a Minute: A vote for 'Black Disability Politics'](#) (18 min. | November 2022)

(Continued on page 38)

Toolkits & Guides

Ableism and Violence: A Plain Language Guide

by Uniting for Change Coalition with support by the Vera Institute of Justice's Center on Victimization and Safety. This resource aims to be a plain language guide to ableism and the ways that ableism contributes to violence against people with disabilities. It is designed to help self-advocates understand ableism and its connection to violence against people with disabilities.

Access from an Interpersonal Angle: Tools for Ongoing Learning

by Disability Rights Wisconsin

From this document's preface: *"When we think about all of the ways that access can be derailed, two acknowledgements seem important. First, there are many ways that good, smart, caring people can get the interpersonal connection wrong. Second, we can each bring a little more attention and humility to our interactions. No one can get it right 100% of the time, but each of us can try to do better more of the time. We can each be a little more curious about what it is like to be the person trying to find the kinds of support that will be personally useful and meaningful."*

Anti-Ableist Glossary of Disability Terms by Sara Acevedo, under a project by the Vera Institute of Justice. The primary and overall aim of this project is to guarantee equality, sustainability, and quality in these alliances by strengthening the communicative ties between service provider organizations and the disabled persons they support.

Disability Justice: An Audit Tool published by Northwest Health Foundation and written by Leah Lakshmi Piepzna-Samarasinha and envisioned by Stacey Park Milbern and Leah Lakshmi Piepzna-Samarasinha. Disability Justice: An Audit Tool is aimed at helping Black, Indigenous and POC-led organizations (that are not primarily focused around disability)

(Continued on page 39)



Chona Kasinger
for **Disabled And Here**

(Continued from page 38)

examine where they're at in practicing disability justice, and where they want to learn and grow. It includes questions for self-assessment, links to access tools, organizational stories and more.

Madness and Oppression Guide a resource on the intersections of mental health and anti-oppression by the Icarus Project

The Icarus Project envisions a new culture and language that resonates with our actual experiences of 'mental illness' rather than trying to fit our lives into a conventional framework. About this document, they write:

"Along the way we've learned that our communities are impacted by societal systems in different ways, and that these differences affect our mental health. Our guides approach important issues such as oppression and intergenerational trauma and invite you to join others in crafting solutions that help transform the health of our communities."

"We hope you will recognize your own experiences in what others have written—and thus discover language to describe your experiences and new tools to maintain your well-being and transform your community."



Chona Kasinger
for **Disabled And Here**

Skin, Tooth, and Bone: A Disability Justice Primer — Sins Invalid

The Second Edition of *Skin, Tooth, and Bone: The Basis of Movement is Our People* is a Disability Justice Primer based in the work of Patty Berne and Sins Invalid. The Disability Justice Primer offers concrete suggestions for moving beyond the socialization of ableism, such as mobilizing against police violence, how to commit to mixed ability organizing, and access suggestions for events. *Skin, Tooth, and Bone* offers analysis, history and context for the growing Disability Justice Movement. \$7.00 to purchase digital copy. \$21.00 + shipping to purchase hard copy

(Continued on page 40)

(Continued from page 39)

Videos

Intersections of Disability Justice and Transformative Justice

(4 min. 19 sec.)

Featuring Elliott Fukui and Leah Lakshmi Piepzna-Samarasinha

No Body is Disposable Series Three short videos from the Barnard Center on Research for Women featuring Stacey Milbern and Patty Berne from Sins Invalid

Roundtable Discussion: Abolition and Disability Justice

(48 min. 44 sec.)Featuring Elliott Fukui, Yolo Akili Robinson, Andrea Ritchie and Leah Lakshmi Piepzna-Samarasinha

Resourcing our Disability Justice

Movements (1 hr. 59 min.)

Featuring Kiyomi Fujikawa

Crip Bits: Disability Justice, Liberation, and Bodies

YouTube Playlist from Sins Invalid featuring six videos of varying lengths on disability justice topics

Transformative Justice in the Lives of Survivors with Disabilities and Deaf Survivors

(1 hr. 27 min.) Featuring Olga Trujillo and Leah Lakshmi Piepzna-Samarasinha



Chona Kasinger
for Disabled And Here

Websites

Affect is a disability-led effort to create resources that amplify multiply marginalized people of color and embody disability justice. In 2019, Affect launched the Disabled And Here Collection, a disability-led effort to provide free & inclusive stock images from their own perspective, with photos and illustrations celebrating disabled Black, Indigenous, people of color (BIPOC). The Disabled And Here collection is published under Creative

(Continued on page 41)

(Continued from page 40)

[Commons attribution](#) licensing, which means you can use, share, and adapt the images for free [with appropriate credit](#).

[Brownstargirl](#) is Leah Lakshmi Piepzna-Samarashinha's website, and a starting point for learning deeply about disability justice. Leah's downloadable [Press Kit and Access Rider](#) is instructive for those who offer live, remote or recorded events. Another of the many useful resources found on this website is [Suicidal Ideation 2.0 - Queer Community Leadership, and Staying Alive Anyway](#).

[Disability Rights Wisconsin \(DRW\)](#)

Disability Rights Wisconsin is a private non-profit organization that protects the rights of people with disabilities statewide.

[Epiphanies of Equity, LLC](#)

ChrisTiana ObeySumner's website. They say that within Social Equity work the north star is disability justice, antiracism, and systems-level reconstruction for equity and justice. Check out their list of articles and videos [here](#). While you're looking at ChrisTiana's work, here are some slides from [an Introduction to Disability Justice](#) presentation that they delivered to the School of Education at Seattle Pacific University. They provide a simplified outline of the principles of disability justice, a comparison of disability justice and Disability Rights frameworks, definitions of related terms, steps for engaging a transformative practice, and more.



Chona Kasinger
for **[Disabled And Here](#)**

Aging and Disabilities Advocates and Allied Professionals Listserv

Did you know End Domestic Abuse Wisconsin has a listserv for aging and disabilities advocates and allied professionals? The Wisconsin Aging & Disabilities DV Advocates listserv is a way to share ideas, raise questions, discuss emerging issues, and exchange resources and training opportunities related to supporting older survivors of abuse. If you would like to join the listserv, please visit <http://lists.wcadvlists.org/listinfo.cgi/aill-wi-wcadvlists.org>.

Kay Ulanday Barrett in Wisconsin

Award-winning poet and disability activist Kay Ulanday Barrett will be a keynote presenter at the Teen Summit in May, 2023. Named as a *Transgender and Gender Nonconforming Writer You Should Know* by Vogue Magazine, [Kay Ulanday Barrett](#) is a poet, essayist, and cultural strategist. Their second book, *More Than Organs* (Sibling Rivalry Press, 2020) received a 2021 Stonewall Honor Book Award by the American Library Association and is a 2021 Lambda Literary Award Finalist.

Their contributions are found in *The New York Times*, *Academy of American Poets*, *Poetry Magazine*, *Colorlines*, *Asian American Literary Review*, *The Advocate*, *Al Jazeera*, and elsewhere. Currently, they serve as a co-curator at The Asian American Writer's Workshop.



Kay Ulanday Barrett

The [Teen Summit](#) will be held May 19-21, 2023 at the Kalahari Resort. The Teen Summit, End Abuse's largest training, is developed by and for young people. It brings together youth, parents, educators, activists, and mentors from across Wisconsin and the surrounding area to learn about individual and community healing, anti-violence work centering those most impacted, and imagining violence-free futures.



End Domestic Abuse Wisconsin
 1400 E Washington Ave, Suite 227
 Madison WI 53703
 608-255-0539
endabusewi.org | riselawcenter.org
ncall.us | ashafamilyservices.org



END ABUSE BOARD OF DIRECTORS

Courtney Olson
 Jane Graham Jennings,
 Chair
 Jennifer Varela
 Kristy Moran
 LaTanya Campbell
 Morgan Young
 Natalia Kruse
 Pamela Johnson
 Samantha Collier

SUPPORT US!

Your gift furthers our mission to prevent & eliminate domestic abuse. To make a donation, [click here](#).

STAY IN TOUCH



Email Signup:

<http://bit.ly/EndAbuseEmailSignup>

END DOMESTIC ABUSE WISCONSIN STAFF

| | |
|---|--|
| Abigail Lezama-Duran, RISE Bilingual Legal Assistant | Kelsey Mullins, Staff Attorney, Underserved Populations |
| Adrienne Roach, ASHA Housing Analyst | Kristin Burki, NCALL Director |
| Ajamou Butler, LTE Prevention Specialist | Kwnwahta Smith, Southern Region Youth Program Coordinator |
| Anna Cash, NCALL Training & Technical Assistance Coordinator | Martie Washington, NCALL Program Coordinator |
| Angie Trudell Vasquez, HR Manager | Molly Stoffen Basarich, RISE Associate Attorney |
| Ann Laatsch, NCALL Justice System Coordinator | Monique Minkens, Executive Director |
| Annette Sauvola, Senior Staff Accountant | Nicole Johnson, Program Capacity & Support Coordinator |
| Antonia Vann, Director of ASHA | Olivia Osborne, Program Capacity & Support Coordinator |
| Betty Brown, ASHA Office Manager | Paz Santiago-Rivera, LTE Tech Support |
| Cody Warner, LGBTQ & Youth Program Director | Robin Dalton, Director of Legal Services |
| Colleen Cox, Education & Training Coordinator | Rosalind McClain, ASHA DV/Elder Abuse Victim Advocate |
| Crystal Ayad, ASHA Lead Advocate | Sara Krall, Homicide Prevention Program Director |
| Daniel Krishnan, Technology Manager | Sara Mayer, NCALL Assistant Director |
| Danny Ho, Leadership & Advocacy Program Director | Sarah Carpenter, Associate Director of Finance |
| Elise Buchbinder, Director of Communications | Sheridan Bearheart, Director of Finance |
| Elizabeth Diaz Lorenz, RISE Bilingual Outreach & Clients Services Specialist | Shawn Muhammad, ASHA Associate Director |
| Gricel Santiago-Rivera, Director of Sustainability | Stephanie Ortiz, Co-Director of Prevention & Engagement |
| Hadiyah Shaheer, ASHA DV Service Victim Advocate | Stephanie Vang, Northern Region Youth Program Coordinator |
| Jenna Gormal, Co-Director of Prevention & Engagement, Policy & Systems Change | Tegan Swanson, Systems Change Coordinator |
| Julie Fisher, Grants & Finance Analyst | Teresa Weinland-Schmidt, Staff Accountant |
| Kari LaScala, Staff Attorney | Valerie Clark, Technology Support Specialist |
| | Victoria Ferguson-Young, NCALL Victim Services Coordinator |