

# Recommendations for Advancing Disability Justice in Oregon and SW Washington

2018



“Knowledge is power, so I will take the knowledge learned and share it.”

- Tamyca Branam Phillips

**Content Notices:** Language about Discrimination\*, oppression, ableism\*, disableism\*, anti-blackness\*, racism\*, colorism\*, cissexism\*, sexism\*, heterosexism\*, classism\*, police violence, school discipline, unemployment, homelessness, institutionalization\*

\*Words with asterisks are included in the glossary at the end of this report. We only include an asterisk next to the first use of each word.

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## Introduction

Almost one out of four Oregonians<sup>1</sup> and approximately one out of eight Washingtonians<sup>2</sup> have a disability, but disabled people are rarely considered as a voting bloc, or even a community. Few nondisabled people have language to describe the experiences of disabled people, and ableism — oppression of disabled people — is rarely acknowledged.

We know communities of color are disproportionately harmed by ableism. Ableism works hand in hand with anti-blackness, racism, colorism, cissexism, sexism, heterosexism, classism, and other forms of oppression. We know almost half of all the people murdered by cops have disabilities, primarily Black, Brown, and Indigenous people.<sup>3</sup> Students of color with disabilities are more likely to be suspended and expelled from school.<sup>4</sup> Disabled people of color (POC) are more likely to be unemployed.<sup>5</sup> On average, Hispanic, African American, and Native American Oregonians earn 20-30% less than white Oregonians.<sup>6</sup> And Black and disabled people are much more likely to be homeless.<sup>7,8</sup>

These broken systems that are hyperfocused on creating easier-to-navigate systems for non-disabled people with disposable income replace traditional, community-based systems. Black and Indigenous cultures practice community care without stigmatizing, othering, or dismissing the value of community members. By being forcefully removed from our land, institutionalized and/or enslaved, and having our communities disrupted and broken up, many of us are now faced with the culture shock of ableism, capitalism, and dehumanization, which tells us that we are worthless despite our

clear resilience in surviving hundreds of years of historic and contemporary trauma.

While we cannot discount what the disability rights\* movement achieved, we still have not reached equity and justice for all disabled people. This is where Disability Justice\* comes in.

Disability Justice is, as defined by prominent Disability Justice organizer and writer Mia Mingus, “a multi-issue political understanding of disability and ableism, moving away from a rights based equality model and beyond just access, to a framework that centers justice and wholeness for all disabled people and communities.”<sup>9</sup>

“Disability Justice affirms that all our bodies are unique, and all our bodies are essential. It welcomes people who haven’t been able to participate. It affirms that disabled bodies aren’t a detriment to the world. They’re an asset. The liberation of people with disabilities is crucial. The Americans with Disabilities Act (ADA)\* and disability rights are also crucial, but Disability Justice builds on that by transforming society to see people with disabilities as having inherent worth.”

- Joel Iboa

“I think [Disability Justice is] another opportunity to recognize the inherent value and dignity of everyone, which conflicts with the ways many of our systems and institutions currently operate. It’s also a chance to recognize the strength in our differences. Validating one another’s Accessibility\* needs is crucial, and it requires that we are part of a community that holds itself accountable to a dynamic learning process. In these ways, Disability Justice feels like truly exciting and revolutionary work to me.”

- Arlene Amaya

### **A Note from Northwest Health Foundation**

Northwest Health Foundation believes every person is valuable and deserves the opportunity to lead a healthy life, whatever health means to them. NWHF also believes when one person or community thrives, all of us benefit. And, in order to achieve health for everyone, all people and communities need to be represented in decision-making positions. Disabled people, especially disabled POC, are severely underrepresented in those positions. So, NWHF decided to convene a Disability Justice Leaders Collaborative to hear from disabled leaders, prioritizing disabled leaders with intersecting oppressed identities, about how best to uplift the voices and leadership of disabled people throughout Oregon and Southwest Washington, particularly in regards to civic engagement.

118 people with disabilities applied to join the Collaborative, demonstrating the interest in and need for investment in this area.

Originally, Northwest Health Foundation planned to invite ten leaders to join. Due to the high number of applications, and thanks to the Collins Foundation's support, we were able to invite more. In the end, NWHF and the Collins Foundation brought 16 disabled POC<sup>10</sup> together for an introductory webinar and four all-day, in-person/virtual meetings. The Disability Justice framework prioritizes the leadership of queer and transgender disabled POC, who are among those most impacted by inequities as a result of their intersectionality\*. In addition to being disabled POC, leaders in the Collaborative also identify as queer, gender non-conforming, youth, houseless, Black, Indigenous, multi-racial, immigrant, refugee, and rural, among other intersecting social identities. Throughout the four convenings, they:

- Discussed visions and strategies for ensuring the needs of disabled people are centered in decision-making
- Deepened and collectively built their understanding of Disability Justice
- Discussed how disability-led organizations can work together in new ways with:
  - Organizations led by communities of color
  - Existing and new disabled, Deaf, sick and neurodivergent\* communities and organizations
  - Leadership programs and funders

These four meetings were very much initial conversations. This report seeks to capture these initial conversations and includes: a Statement of Values, Recommendations, a few resources to learn more about Disability Justice and Accessibility, and a Glossary.

Happy reading!



# Statement of Values

As a Collaborative of disabled POC living in Oregon and Southwest Washington, we value Disability Justice as a liberatory framework. By “liberatory framework” we mean a way of living together that allows us to be free. To us, Disability Justice is a world where disabled people, especially those of us with intersecting oppressed identities, have good quality of life, community, the resources we need, and the opportunity to contribute to society in ways we desire and lead our lives in optimal ways.

As a group, we hold many complexities. Just because we all have disabilities and are people of color does not mean we all have the same political beliefs or agree on how social change is created. For example, some of us believe institutions, such as our current systems of governance, can be fixed by placing people with integrity in leadership, while others believe these institutions must be abolished. For that reason, creating a shared statement of values has been hard won.

At the same time, it felt important to share with our communities what we believe in. We recognize our liberation depends on one another and our willingness to strive toward common goals together.

## **Shared Values**

- We value the expertise of disabled POC. We are the best experts on our own lives, and we have unique and important contributions to make to the world. There is no one who knows more about disability issues than disabled people. This may

not seem profound, but most organizations serving disabled people are not actually run by us. They are run by folks with credentials that do not include lived experience, like parents of disabled people, “professionals” in disability service fields, and other non-disabled people.

- When an organization does include disabled people on staff or on the board, they are most frequently white disabled people. Given that ableism also impacts communities of color, this is not okay. We believe the expertise and experience of disabled POC should not be excluded, but included and centered, as long as it is not done in a tokenizing\* way.
- We believe disabled people are whole and perfect as we are. Many times, funders and government, as well as family members and others, understand the “problem” of our lives as us — our own bodies and minds (bodyminds\*) — instead of the systems that exclude us. We are not the problem. Our bodyminds are not the problem. Rather, the problem is an inAccessible society, as well as a lack of resources and culturally-competent support. The disability community calls this the “social model of disability\*.” The assumption our bodyminds need fixing is called the “medical model of disability\*.” We value the social model. We do not have to change our bodyminds to be worthy of inclusion, love, and justice.

“There’re two models of disability: medical and social. Medical assumes if you weren’t disabled, there wouldn’t be a problem. The social model is that society disables us. If we change the way society is, people wouldn’t be disabled. I don’t call people able-bodied who are not disabled. I call them not disabled. Or enabled. It’s not a problem with our bodies or minds, it’s a problem with society.”

- Rory Judah Blank

- We value radical, full Accessibility in our communities — for everyone. Creating an environment where everyone can participate is the first step towards creating a more just world. Accessibility takes resources and commitment. We want state and local government agencies, nonprofit organizations and community groups, and employers to specifically identify Accessibility as part of their business policies. We also want groups to allocate adequate resources for Access by thinking about what is needed ahead of time, not after the fact.
- We value specificity and meaning what you say. Accessibility means different things to different people. When it comes to talking about Accessibility, our lives require specifics to know if something can work for us. For example, telling us “the building is ADA accessible” is not helpful. We need to know specifics like the width of doorways and walkways, whether American Sign Language (ASL) interpretation will be available, whether cleaning products used in the space are scent-free, etc. This need for specificity translates to our political lives as well. Generalities and vague promises do not work. Good

intentions aren't good enough. We need positive impact.

- We value intersectionality and the centering of multiply-oppressed voices, especially those most marginalized, such as queer, trans disabled POC, Black, Brown, and Indigenous folks, disabled immigrants, disabled sex workers, justice-involved individuals, and all our kindred. We know that we cannot be free until we dismantle all forms of oppression. We value “nothing about us without us”\*. Those who are most impacted by an issue should be the ones to speak to it.
- People think our main concern is getting the services we need. We are not just recipients or beneficiaries. We are a crucial and contributing part of our collective, greater community. Services are not at the center of our lives. Our contributions are at our center and at the center of our community. It's also important to note that the services we request should be considered basic needs, much like doors, chairs, or lights, and when we are rejected and othered for requesting these services, it often means we can't access food, water, shelter, or community, and it devalues our humanity.

“As a child born in 1943 in poverty in the U.S., I was never valued. The only people who were important and listened to — who had power — were people with capital. Money being more important than people who are disabled is a TOP-DOWN system that exists to this day, that needs to be changed. People actually don’t know what they are doing, in being top-down in attitude and action. I do want to thank anyone and all who do care, who do anything for people who are disabled, but I also recommend they explore the treasures we are as a gift to this changing world.”

- Grace Eagle Reed

- We believe our Disability Justice work is naturally connected to ideas of restorative justice\* and transformative justice\*, because these frameworks all hold that everyone is deserving of support, community and having their humanity recognized. We reject the idea that “some people” are disposable, and we want society to find ways to include all of us. This also describes anti-ableism\*.

“We as a society have a longstanding need for trauma-informed care (“TIC”). TIC, and it’s qualities and services, are currently being spread and implemented. I understand what this need is, as I am representative of this need in Oregon. TIC can be inaccessible and hard to find as it is fairly new and the need is great. I aspire to continue to serve DJ with solidarity, and with my own ability and experience in a TIC-aligned healing therapy, if allowed.”

- Anonymous Collaborative Leader

# PRINCIPLES FOR RESPONSIBLE COMMUNITY WORK

Compiled by Lydia Grijalva

## 1) EXPECT TO BE UNFINISHED

We know our work will never be finished. We acknowledge how much we will always have to learn, and that our knowledge and understanding will never be complete.

## 2) COMMIT TO CONTINUOUS UNLEARNING

Systems of oppression are deeply ingrained in not just our society and culture, but in each of our minds. It is necessary to continuously unlearn these oppressions and recalibrate.

## 3) PRACTICE EMOTIONAL RESPONSIBILITY

Folks need to ensure that they're not centering their guilt as we continue to hear about ways folks are harmed by the systems we all participate in. This sometimes means stepping away from the work to reflect and redirect energy.

## 4) BE BEHIND THE SCENES

Do the work, like ensuring Accessibility, procuring food, providing childcare, etc., that honors the humanity of oppressed people. This behind-the-scenes work needs to be done, even when organizations or event planners don't receive credit for it.

## 5) SUPPORT LEADERS

Just centering disabled POC in leadership roles isn't enough. Organizations and movements also need to provide the supports these folks need to be successful leaders — as defined by them.

## Recommendations

Leah Lakshmi Piepzna-Samarasinha says, “we need wild disability justice dreams.” We believe this wholeheartedly — that disabled POC hold a critical key in visioning and leading our collective liberation. We believe change agents accountable to us should center the leadership and lived experiences of disabled Black, Brown, Indigenous folks, immigrants and refugees. There are many ways to do this, and it can be done at all levels. Our Collaborative had many, many thoughts about ways to advance Disability Justice leadership. Below are some of our recommendations:

### **RECOMMENDATION #1: MAKE YOUR ORGANIZATIONS MORE AWARE OF ABLEISM, AND PRACTICE ANTI-ABLEISM AND ACCESSIBILITY**

One of the hardest things about anti-ableism work is people don't always know what ableism looks like or how it is practiced. So many times people think the hardships disabled POC face are inherent to our bodies or minds, when really many of the struggles we face are created by our environments. We recommend organizations take on a process similar to the one Northwest Health Foundation took on: form a board committee to better understand how ableism impacts the work, recruit disabled board members and staff, coordinate internal and external trainings, host reading groups and provide anti-ableism materials, and ask disabled POC what the agenda should be for movement-building. Understanding WHY you are doing something is important. We see a great need in non-disability-specific communities for anti-ableism classes and



workshops. It's also beneficial to customize anti-ableism trainings for specific sectors and industries (e.g. an anti-ableism training for health equity groups, an anti-ableism training for racial justice groups, an anti-ableism training for tech start-ups, etc.).

We also strongly recommend predominantly white, disability-led organizations take disabled POC-led courses and workshops and engage in long-term cultural competency improvement for challenging white supremacy culture, not only in their own organizations but also to build their own capacity for being in community with disabled POC. They should also create a plan that includes bringing more disabled POC voices to the table.

“We need culturally-specific organizations to use Disability Justice as a gateway to doing racial justice work, and disability-specific organizations to use racial justice as a gateway to doing Disability Justice work.”

- Rory Judah Blank

Anti-ableism also means practicing Accessibility. This doesn't just mean meeting ADA requirements for restrooms and parking spaces. It also means carving out a budget for Access needs\*, offering opportunities for people to communicate what their Access needs are, providing interpretation and captioning, working to make spaces fragrance-free, taking more breaks during long meetings, ensuring screen readers work with your website, etc.

## **Food for Thought**

What work do you and your organization need to do to better understand Disability Justice? How are you committed to

combating ableism? What do anti-ableism practices look like to you? Are your physical and digital spaces Accessible? Are your meetings and events Accessible? Do you provide accommodations for the employees who need them?

## **Action Steps You Can Take**

- Commit to learning more internally. Host internal anti-ableism trainings. Form a study group within your organization to read and discuss articles and books by disabled POC about Disability Justice, anti-ableism, and Accessibility.
- Open your anti-ableism trainings and/or study groups to peer organizations.
- Create a plan to recruit and hire disabled POC for open positions.
- Ensure positions pay living wages and have benefits.
- Ensure disability representation is an organizational/business/community group practice.
- Build in time for personal storytelling and sharing of lived experience, as well as process.
- Appreciate the diversity within the disability community. There are an infinite number of experiences and identities. We cannot flatten or simplify this. “No body left behind” is a central tenet of Disability Justice.
- Hire consultants to conduct Accessibility audits.
- Create a budget to meet Access needs.
- Make asking about Access needs a habit, and then do the work to meet them.

“Where peers are senselessly, crudely, criminally taken away from where they belong, to wither and all together fail, away from their own heart, their hearts, their loves, their dreams, their rich talents, their Access needs, their life—in true definition, I hold the space for you to come back.

‘Never lose hope, my heart. Miracles dwell in the invisible.’  
- Rumi”

- Anonymous Collaborative Leader

## **RECOMMENDATION #2: BUILD AN INFRASTRUCTURE OF SUPPORT AND RESOURCES IN ORDER FOR DISABLED PEOPLE OF COLOR TO EMBRACE OPPORTUNITIES, INCLUDING LEADERSHIP**

People of color with disabilities face multiple forms of overlapping oppression, and many of us are in survival mode or crisis through no fault of our own. As it is for many communities of color, our history is deeply etched by institutionalization. For many years, disabled people were separated at a young age from their families and communities and forced to live in institutions like state hospitals, residential schools, and nursing facilities. Over the last twenty years, disability community has done much to advocate for community settings. (No one should have to live in an institution just to access disability services that could be provided at home or in mainstream classrooms.) Even so, society gives little resources to support disabled people to have good quality of life. We want disabled POC to be leaders, but we haven't created the

infrastructure to support people to be in leadership roles in ways that aren't tokenizing. Imagine being on a fixed income<sup>11</sup> and/or homeless and trying to run for office. It'd be near impossible, not because of a lack of competency, but because of a lack of resources, safety, time, and spoons\*.

“I want to be a part of policymaking. I am interested in participating in advocacy and policy change, because our voice is not there. When we put more people who experience the problem in decision-making positions, we'll get more solutions to fix the problem.”

- Saara Hirsi

If we want to see disabled POC in leadership roles, we must first talk about supporting disabled POC in living their lives.

We need supporters to allocate necessary resources and create infrastructure that supports disabled leaders of color. As stated in our “Shared Values” section above, disabled POC are not just recipients and beneficiaries of services. However, we do need these services to participate and lead.

We know private philanthropy and the nonprofit sector cannot replace government-funded lifeline services (healthcare, door-to-door transportation, subsidized housing, etc.). We also know that these systems are inherently broken and require innovation, and that part of the reason change agents have not focused their efforts on transforming these systems is unexamined ableism and bias. Even though laws are in place to protect our rights, they aren't always implemented or enforced. So, in reality, we are often not

protected. Alarming, society has self-driving cars and smart refrigerators, but a lot of medical equipment disabled people use every day has not had a real change in decades.

“I envision everyone receiving holistic healthcare and being housed. Unfortunately, institutionalized oppression is real, and this crushes our bodies, minds, and spirits. If we get locked out of healthcare and/or housing, it’s almost impossible to develop sustainable connections with those around you, get a job, and so many other things. When someone shows up and is deemed to have red flags – you’re a person of color, you don’t have insurance, you don’t have a place to live, you have depression, chronic pain, you’re trans, queer, you’ve been on opiates, you experience post-traumatic stress, etc. – unless you have a really good support network, advocates, and, in my case, help from my congressional representative, you get blown off and end up dead, on the streets, or in prison. When I first sought treatment after being hit and dragged around a corner by a station wagon while riding my bicycle, I was blown off, yelled at, humiliated, among many other horrors. For example, it took three years to get a cast on my broken hand. So, it’s really important to me to pass Health Care for ALL Oregon and on the West Coast, while at the same time changing the way people think about healthcare. Many folks are taught to run to the doctor’s office for every piece of advice about how to take care of our bodies, but there’s so much people can do themselves just by changing what we put in our bodies and other daily habits.”

- Nico Serra

## Food for Thought

How are you supporting disabled POC? Is your social change agenda inclusive of disability issues? How can you improve the ableist world disabled POC live in?

## Action Steps You Can Take

- Think about what could ease the struggle and increase the freedoms of disabled POC.
- Invest resources and time in improving and changing the systems disabled POC must contend with to acquire support.
- Advocate for, fund, and/or build affordable, Accessible, quality housing.
- Employ disabled POC and provide for their Access needs at work.
- Create an emergency resources fund that is reasonably available for people experiencing emergency needs. This might include a crisis line that serves to connect people with and without resources. For example, if someone needs a wheelchair and another person has a wheelchair, linking the two provides the Access needed.
- Identify, and create a pool of, attorneys at law who are accessible and Accessible to disabled POC. A pool of attorneys could and would help influence employers, corporations, public institutions and their employees, and others to follow civil rights\* laws. These attorneys should be of the mind to serve protected classes of people, such as disabled POC, who may be experiencing civil rights violations. They should also understand the process disabled people, those with added vulnerability, and underrepresented or

marginalized people must go through to obtain services. A member of the pool could be consulted by folks encountering systemic barriers to Access. The attorney pool could have law-minded assistants and advocates. Attorneys could be available, as the need arose, to counter illegal Discrimination and injustice before it is too late.

- Train people to be anti-ableism allies who recognize and respect disabled POC.
- Work across movements, sectors and industries to innovate, elevate, promote and optimize the quality of life for disabled POC. For instance, this could look like engineers, architects, marketers, and agricultural scientists partnering with a local group of disabled POC who show interest in diminishing food deserts.

### **RECOMMENDATION #3: FUND LEADERSHIP DEVELOPMENT FOR DISABLED PEOPLE OF COLOR**

Typically, when people think of a leader, they think of someone who is male, charismatic, speaks well in public, is tall, physically fit, etc. We need people to reimagine and reestablish the boundaries of what they understand leadership to be. Imagine crip\* or sick leadership, mad or multiply neurodivergent leadership, Deaf leadership, blind leadership, intellectually-disabled leadership, femme leadership, Black and Indigenous leadership, women of color leadership, non-binary leadership, immigrant leadership. Our disability communities are leaderful. To us, leaders are people who give a ride so someone can come to a meeting, explain things in Accessible words (plain language\*), send out the agenda and reminder messages, cook the meal, give and receive feedback, and

love fellow disabled people. Everyone — truly everyone — can be a leader in some way meaningful to them. We value interdependence, and needing support does not make a person less of a leader if they want to be. We all need support. This is a core tenet of Disability Justice: we see potential for everyone to live autonomously and contribute to their communities, even those so othered they've been told they're not even considered human, worthy of connection, or capable of leadership.

“I envision Disabled People of Color winning political positions, influencing decisions, and deepening our overall capacity as a community.”

- Myrlaviani Perez-Rivier

There are many mainstream leadership development programs available, some that even share a more expansive view of leadership, but a scant few are Accessible to disabled POC. Programs frequently require 8+ hour training days that begin at around 8 AM, are consecutive multi-day sessions, have financial fees associated with them, and more. In response, funders and organizers frequently choose to create disability-specific trainings, which can be helpful in terms of Access, but still leave out disabled POC from these other trainings. We know from the work of Black activists who worked to end segregation that separate is not equal. We recommend investing in the capacity-building of leadership development programs to serve disabled POC. One best practice for this is to hire disability Access consultants to do Access audits and program reviews, and partner with these consultants over time.

Increasing the capacity of our communities to include us in all of our



identities is long-term work. For that reason, we also recommend more short-term, immediate strategies, such as creating funding streams for disabled POC to pursue leadership development opportunities Accessible to them. Even if mainstream leadership programs become more Accessible, we know many disabled POC will continue to need more customized development reflecting a person-centered approach and philosophy. We recommend creating opportunities for disabled POC to receive coaching, mentorship, and Access to resources we need to increase skills. As society has taken steps to “mainstream” or integrate communities, we have seen support for community-specific programs and spaces dwindle. We do not want this. We want to have vibrant disability community spaces and better access to mainstream leadership programs.

“I would like to improve my leadership skills to be able to serve the disabled community at large, to help create and change policies at the local and state level that impact disabled peoples’ daily life. Also, I would like to share my experience and train disabled youth to become independent and take command of their lives.”

- Waddah Sofan

## **Food for Thought**

How do you understand leadership, and is that understanding inclusive of disabled POC? How are you and your work accountable to disabled POC? Are you reading texts by disabled POC? Are you reading about civil rights? Are you hiring Disability Justice or Accessibility consultants to make your programs more Accessible? Are you expanding opportunities for disabled POC? Do

you offer Access stipends people can use to pay attendants, childcare providers, transportation providers, and others to participate in leadership development?

## **Action Steps You Can Take**

- Hire a disability Access consultant to conduct an audit of your leadership program and recommend improvements. Support leadership programs in becoming Accessible to disabled POC.
- ◆ Hire disabled POC to facilitate leadership programs.
- Create funding streams for disabled POC to pursue leadership development opportunities Accessible to them.
- Create fellowships for Disability Justice leaders to work on projects and receive training and support.
- Create training and networking opportunities for disabled POC to learn new skills and network/build with others.

## **RECOMMENDATION #4: SUPPORT DISABILITY JUSTICE MOVEMENT-BUILDING**

Disability tends to be an untouched area in philanthropy, with many funders thinking of the topic as a medical or healthcare issue, not an equity concern or a political constituency. Most Disability Justice work is unfunded and happens on the individual level with cultural workers and activists doing projects and writing intermittently. There are very few formal, ongoing Disability Justice projects, largely because of a lack of support. Through the brilliant tactical and political leadership of Patty Berne and Leroy Moore, Sins Invalid was formed as a Disability Justice nonprofit project staffed by disabled, queer POC ten years ago in the San Francisco Bay area.

It is the only formal organization we are aware of, even a decade later.

It is imperative to support disabled leaders of color to come together and work together. More conversations are necessary about what is needed in Oregon and Southwest Washington. Additionally, through the Disability Justice Leaders Collaborative, Collaborative members identified multiple initiatives they would like to see implemented and are open to taking on: ongoing Disability Justice convenings, supporting disabled POC to run for office, cultural work projects, survival guide resource websites, coalition-building, and more. These initiatives take financial resources to make happen.

At the end of the day, we are talking about movement-building. Movement-building takes time, money, space, and spoons. There are a lot of internal conversations that need to take place among disabled POC. We need time and space to work things out with one another. Due to the pervasiveness of oppressive systems, and the ways that oppressed people are socialized to internalize blame for our oppression, we need to unlearn the tendency to make excuses for our oppression and those who share our oppressed identities. This often manifests as horizontal oppression\* within and between disability communities, which continues to be an issue that delays our success. We ask our accomplices to support our relationship-building and to refrain from tokenizing disabled (and otherwise oppressed) people, as it plays into this internal tension.

“Disability Justice demands, by way of compassion and caring communities, systems change, institutional reform, and a new notion of private and public market performance defined, owned, operated, and valued by community members most impacted. Disability Justice is all about creativity and innovation. It’s invigorating and demanding. It means you have to show up and demonstrate radical self-love and compassion, which are founded on standards of quality caring and intimate connection. We account for the complex strata of universal Access, intersectionality of race, disability, gender, and religion with the never-ending and always-loved question of “What am I missing here, right now? Do we have what we need?” We are the road builders and bridge architects we need. I feel we are ready for Us.”

- Myrlaviani Rivier-Perez

## **Food for Thought**

What inspires you about Disability Justice? How can you support Disability Justice movement-building in your community? How does Disability Justice support all of us getting free?

## **Action Steps You Can Take**

- Create opportunities for disabled POC to work together via discretionary funding streams. Small stipends and grants can go a long way.
- Send disabled leaders of color to conferences and events where they can meet others.

- Offer free space and Access support to Disability Justice organizers and Access support when you can.
- Support disabled POC to build multicultural, cross-disability coalitions.

## **RECOMMENDATION #5: TRACK DISABILITY-RELATED OUTCOMES, RESULTS AND IMPACTS**

One of the biggest barriers to building Disability Justice is the lack of data we have about disability, especially regarding disabled POC. Information and data are powerful tools. We encourage foundations, nonprofits, and other advocates to begin including disability metrics in their data analytics programs and research. This allows us to determine if our communities are adequately represented and, if not, the avenue to identify programmatic or operational gaps. Further, we strongly encourage state agencies, such as Oregon Health Authority, as well as all Oregon counties and cities or municipalities, to sufficiently resource and build the infrastructure for collecting disaggregated data and implement measurable and evaluable programs, tools, instruments, or mechanisms as deemed effective and efficient by diversity, equity, and inclusion leaders, researchers, and coordinators. Disabled POC should be involved in data planning.

### **Food for Thought**

Are you including disabled POC in designing your research? How are you measuring the success of your efforts? Are you tracking disability in program evaluation and reporting? What are your principles and practices of transparency and accountability? Do your research methodologies reflect collaboratively-based,

participatory research principles and best practices?

## Action Steps You Can Take

- Funders create a pilot project with select grantees to report how many of their board members, staff members, and/or clients are disabled POC and track the impact of this representation.
- Researchers rooted in community-based, participatory research philosophy and design meet with Disability Justice leaders to collaborate on what information would be helpful to collect at the outset of program development.
- State and local municipalities sufficiently allocate resources for participatory research programs. Allocating resources demonstrates to our community a willingness to learn about our needs.

## Closing

Thank you for reading our recommendations! Now, we urge you to act. We believe wholeheartedly in the potential Disability Justice has to transform the work we do. Disability itself challenges every notion society has about productivity, value, beauty, worth, and more. Disability Justice isn't just liberation for disabled POC — when we live in a world where all bodyminds are celebrated and supported, it creates more freedom for everyone.

We look forward to collaborating with you to make Oregon and Southwest Washington more Accessible and more inclusive, and

its leadership more crip, more neurodivergent, more queer, more Brown — in short, more reflective of us. Our revolutionary futures depend on it!

## **Resources to Learn More About Disability Justice and Accessibility**

These are the books and articles we read and discussed as a Collaborative. We found them useful. We hope you will, too.

**“Disability Justice: A Working Draft”** by Patty Berne

<http://sinsinvalid.org/blog/disability-justice-a-working-draft-by-patty-berne>

**“Changing the Framework: Disability Justice”** by Mia Mingus

<https://leavingevidence.wordpress.com/2011/02/12/changing-the-framework-disability-justice/>

**“Fragrance Free Femme of Colour Genius”** by Leah Lakshmi

Piepzna-Samarasinha

<http://brownstargirl.org/fragrance-free-femme-of-colour-genius/>

***Skin, Tooth, and Bone — The Basis of Our Movement is Our People: A Disability Justice Primer*** published by Sins Invalid

**“26 Ways to be in the Struggle Beyond the Street,”** Contributors:

Piper Anderson, Kay Ulanday Barrett, Ejeris Dixon, Ro Garrido, Emi Kane, Bhavana Nancherla, Deesha Narichania, Sabelo

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Yu-lan Price

<https://drive.google.com/file/d/0Bzyi8YMLtF11c0V4dW9IalZCaW8/view>

**“10 Ways We Can Make Leadership Accessible for Sick People in Activism”** by Katie Tastrom

<https://thebodyisnotanapology.com/magazine/10-ways-we-can-make-leadership-accessible-for-sick-folks/>

This list is not exhaustive. There are hundreds more articles, blogs, books, videos, trainings, etc. about Disability Justice and Accessibility, and we encourage you to do your own research.

## Glossary

**Ableism** - A system of oppression against disabled people; a worldview that posits non-disabled people as superior to disabled people

**Accessibility** - How available and understandable a physical or virtual space, process, performance, idea, etc. is to people with different physical, mental, and emotional needs

**Access Needs** - What someone requires to fully participate in an event, discussion, activity, opportunity, etc. (e.g. dimmed lights, a quiet space to take breaks in, ASL interpretation, a chance to state the need)

**Americans with Disabilities Act (ADA)** - Signed into law in 1990,



the Americans with Disabilities Act prohibits Discrimination against disabled people

**Anti-ableism** - Acting to challenge and end ableism so that disabled and nondisabled people have equal power and rights

**Anti-blackness** - Discrimination against and oppression of Black people

**Bodyminds** - The mind and body as a single unit; people are both bodies and minds, and those two aspects of humanity cannot be separated from each other

**Cissexism** - Discrimination against transgender people

**Civil Rights** - A set of personal rights designed to be recognized by governments; usually requires legal-based advocacy to counter that your rights are not being recognized

**Civil Rights Act of 1964** - Important civil rights law that outlaws discrimination based on race, color, religion, sex, age, or national origin

**Classism** - Division of people into social classes, which are arbitrary, superficial, and hierarchical. This is followed by Discrimination against people in “lower” social classes, who often labor for their wages and/or have less wealth.

**Colorism** - Discrimination against people with darker skin tones, including among people within the same ethnic or racial group

**Crip** - An in-community term reclaimed by disabled people that derives from cripple, akin to a lesbian using the word dyke

**Disability Justice** - As defined by Mia Mingus: “a multi-issue political understanding of disability and ableism, moving away from a rights based equality model and beyond just access, to a framework that centers justice and wholeness for all disabled people and communities”

**Disability Rights** - A movement that gained traction in the 1970s to advance civil rights for Americans with Disabilities. The passage of the Rehabilitation Act of 1973, the Americans with Disabilities Act of 1990, the Olmstead Decision in 1999, and other rights-based victories support disabled people. It's leadership has predominantly been white, disabled people.

**Disableism** - A system of oppression against disabled people; a worldview that posits disabled people as inferior to people who are not disabled

**Discrimination** - Behavioral conduct, conscious or not, which is prejudiced, biased, or exclusionary, and disadvantages or harms an individual or group of people

**Gatekeeping** - The act of withholding or controlling information or access, usually done by folks who have more access to privilege, social capital, or proximity to a non-oppressed identity.

**Heterosexism** - Discrimination against relationships that are not heterosexual and the people who are in these relationships

**Horizontal Oppression** - Oppression within communities. For example, within the disability community, if a person who uses a wheelchair oppresses an intellectually-disabled person, that is horizontal oppression.

**Implicit Bias** - The unconscious prejudice we all have instilled in us just by living in the society that we live in. Everyone has implicit biases, but we can minimize their negative effects by recognizing them and working every day to change our patterns of thinking.

**Institutional Bias** - An infrastructure or institution (e.g. school, justice system, state government), rather than a sole individual, creates barriers for certain groups of people. For example, this term can be used to describe the way a government prioritizes residential living in institutions instead of community living.

**Institutionalization** - Placing (often forcing) someone into a residential institution. For example, in the 1800s and 1900s, Native American children were forced into residential boarding schools by the American government.

**Intersectionality** - Framework established by Combahee River Collective, Kimberle Crenshaw and other Black Feminists and womanists to describe a need for multi-issue agendas. Crenshaw created this term to draw attention to the fact that Black women experience both racial and gender-based oppression that is more than the sum of the two, though it has been co-opted for other movements.

**Medical Model of Disability** - A way of thinking and talking about disability that positions it as a medical problem to be cured

**Neurodivergent** - When someone's mind works in a way that isn't considered "typical" (Antonym: neurotypical)

**Neurodiversity** - A celebration and recognition of the broad spectrum of minds that work in different ways. It challenged dominant culture understanding that there is no "right" or "wrong" brain, just a diversity of them.

**"Nothing About Us Without Us"** - A rallying cry of the disability rights movement, meaning disabled people should always be involved in making any decisions that might impact them

**Oppression** - Cruel and unjust treatment

**Performative Allyship** - When somebody who wants to appear helpful performs a visible gesture of "allyship" for selfish reasons in order to gain social capital, favor, or favors, generally lacking regard for how others are affected by their action.

**Plain Language** - Written and spoken language that is simple, clear, and easy to understand. Some people believe this is at 4th grade reading level, others at 6th or 8th.

**Prejudice** - Disliking another person or group because of perceived ideas about that group. Prejudice defies reason. Prejudice and power together are very harmful, disabling, and create oppression.

**Racism** - Discrimination against people based on their race and/or ethnicity

**Restorative Justice** - A community-centered approach to rehabilitation and healing for justice-involved people

**Sexism** - Discrimination against people based on their gender and/or sex

**Social Model of Disability** - A way of thinking and talking about disability that positions it as an aspect of identity

**Social Security Disability Insurance (SSDI)** - Social Security Disability Insurance is a monthly stipend supplied by the government. In order to qualify for SSDI payments, an individual has to have worked for a certain number of years and contributed to the Social Security trust fund before they became disabled.

**Supplemental Security Income (SSI)** - Supplemental Security Income is a monthly, needs-based stipend supplied by the government. In order to qualify, an individual must have less than \$2,000 in assets and a very limited income. In Oregon, the maximum monthly SSI payment is \$735.

**Spoons** - A metaphor created by Christine Miserandino and chronically ill/sick communities to describe energy level. For example, someone might say, “I don’t have enough spoons to do that today.” This is synonymous with “I don’t have enough energy to do that today” or “I’m too tired/sick/stressed to do that today.”

**Tokenization** - Putting a person who is a member of an oppressed group into a position where they are representing an entire marginalized group. Tokenized folks are often forced to play into harmful stereotypes and relational power-dynamics in order to simply maintain, or to gain security in, their position. This perpetuates harm all around.

**Tone Policing** - Oppressed people are often (rightfully) angry, because they are oppressed. If a person is speaking of their oppression with anger, and someone who does not experience that oppression accuses them of weaponizing knowledge, that is tone policing.

**Transformative Justice** - A strategy of responding to conflicts that uses values and tactics of restorative justice beyond the criminal justice system

**Weaponizing Knowledge** - When folks who don't experience an oppression use their knowledge of that oppression for personal gain, such as a promotion or social capital, instead of to ensure the safety of those most impacted. For example, when folks engage in performative allyship, they often weaponize their knowledge of the terms used to fight for liberation. This harmful behavior is extremely common.

## Notes

<sup>1</sup> Oregon Office on Disability and Health. 2016. Disability in Oregon: 2016 Annual Report on the Health of Oregonians with Disabilities. Portland, OR: Institute on Development & Disability, Oregon Health & Science University.

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OHSU's Behavioral Risk Factor Surveillance System (BRFSS) Survey asked seven questions about disability:

1. Are you limited in any way in any activities because of physical, mental, or emotional problems?
2. Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone?
3. Are you blind or do you have serious difficulty seeing, even when wearing glasses?
4. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?
5. Do you have serious difficulty walking or climbing stairs?
6. Do you have difficulty dressing or bathing?
7. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?

<sup>2</sup> Washington State Division of Vocational Rehabilitation. 2017. Disability & DVR Statistics Report.

American Community Survey participants could self-select six types of disability: hearing difficulty, vision difficulty, cognitive difficulty, ambulatory difficulty, self-care difficulty and independent-living difficult.

<sup>3</sup> Ruderman Family Foundation. 2016. "The Ruderman White Paper on Media Coverage of Law Enforcement Use of Force and Disability." [http://rudermanfoundation.org/wp-content/uploads/2017/08/MediaStudy-PoliceDisability\\_final-final.pdf](http://rudermanfoundation.org/wp-content/uploads/2017/08/MediaStudy-PoliceDisability_final-final.pdf)

<sup>4</sup> Klein, Alyson and Sarah D. Sparks. 2018. "Discipline Disparities Grow for Students of Color, New Federal Data Show." Education Week. <https://www.edweek.org/ew/articles/2018/04/24/discipline-disparities-grow-for-students-of-color.html>

<sup>5</sup> Alston, Reginald J. and Diane L. Smith. 2008. "Employment Disparities for Minority Women with Disabilities." *Impact* 21, no. 1 (Summer/Fall 2008): pp 16-17. <https://ici.umn.edu/products/impact/211/211.pdf>

<sup>6</sup> Rogoway, Mike. April 24, 2018. "Oregon's economy booms but racial and geographic disparities increase." *The Oregonian*. [https://www.oregonlive.com/business/index.ssf/2018/04/oregons\\_economy\\_booms\\_but\\_raci.html?fbclid=IwAR0Kprpr2eY9SrP1kM1z0TZBzb8D7rhVMc6oDLGq3YS-5ScYeiyxE2GPHA0](https://www.oregonlive.com/business/index.ssf/2018/04/oregons_economy_booms_but_raci.html?fbclid=IwAR0Kprpr2eY9SrP1kM1z0TZBzb8D7rhVMc6oDLGq3YS-5ScYeiyxE2GPHA0)

<sup>7</sup> Diamant, Michelle. 2009. "More than Two-Fifths of Homeless Have Disabilities." *disabilityscoop*. <https://www.disabilityscoop.com/2009/07/16/homeless-report/4153/>



<sup>8</sup> Scott, Gregory C. 2017. “Homelessness has a Black Face.”  
Huffpost. [https://www.huffingtonpost.com/entry/homelessness-has-a-black-face\\_us\\_58b5fea2e4b0658fc20f9b32](https://www.huffingtonpost.com/entry/homelessness-has-a-black-face_us_58b5fea2e4b0658fc20f9b32)

<sup>9</sup> Copley, Theo Yang. 2011. “What Disability Justice Has to Offer Social Justice.” Grassroots Institute for Fundraising Training. <http://www.grassrootsfundraising.org/2011/11/11-3-what-disability-justice-has-to-offer-social-justice-by-theo-yang-copley/>

<sup>10</sup> Unfortunately, two of these leaders had to drop out over the course of the Collaborative convenings. We still want to recognize and appreciate their early contributions to the Collaborative.

<sup>11</sup> Disabled people who can't work a full-time job, or can't work at all, often rely on Supplemental Security Income\* and/or Social Security Disability Insurance\*. This money is needed and helpful, but it is often puts disabled POC below the poverty line, especially considering the support and medical equipment they might have to pay for to meet their basic needs.