



Disability Justice and Health Equity for Indigenous People who have Disabilities

American Indian Disability Summit 2025

Presenters and Purpose

Mellie Adu, Arizona Statewide Independent Living Council (AZSILC), and Melanie Mills, The Arc of Arizona, are members of the Arizona State Alliance Team for the Bridging Aging and Disability Networks for Individuals with Intellectual and Developmental Disabilities Community of Practice.

The goal of this team is to strengthen the collaboration between aging and disability networks to better support individuals with I/DD and their families as they plan for their future across the lifespan.

This presentation is given on behalf of the Equitable Access to Care Workgroup of the Arizona State Alliance Team.



Kara Thrasher (AZSILC) and Eileen Tohonnie (Assist to Independence and AZSILC) and are Diné people who work within the Arizona disability community. Kara works on a statewide basis, and Eileen lives and works on Navajo Nation, leading a Center for Independent Living which provides services to Hopi, Kaibab Band of Paiute Indians, and Navajo Nation members who have disabilities, residing across Northern Arizona.

Disability Justice: Moving Beyond Disability Rights

- The Disability Rights Movement established civil rights for people who have disabilities, and is comprised of disability advocates, activists, and allies who fight for more equitable access, inclusion, and opportunity, for people who have disabilities.
- While the Disability Rights Movement has succeeded in making truly significant gains by establishing critical policy and laws, those important achievements have not alleviated the harmful and historically oppressive influences of ableism such as bias, disability hierarchy, and social stigma.
- The Disability Rights Movement created a solid foundation from which to build, and the Disability Justice Movement is building more intentionally and holistically.

Disability Justice: A Work in Progress for 20 Years

- Disability Justice is a term that was coined in 2005 by Sins Invalid, which is a collective of disabled, queer women of color, including Patty Berne, Mia Mingus, and the late Stacey Milbern.
- Disability Justice builds on the Disability Rights Movement, by centering the intersectional experiences of people who have disabilities who also belong to other marginalized communities, and the ways in which systems of oppression reinforce one another.
- Marginalized communities are groups of people who experience social, economic, political, and systemic barriers, disadvantages, and/or exclusions from mainstream society, which limit their access to resources, opportunities, and power.

Disability Justice: A Working Draft

“Disability justice holds a vision born out of collective struggle, drawing upon legacies of cultural and spiritual resistance. Within a thousand underground paths we ignite small persistent fires of rebellion in everyday life. Disabled people of the global majority — Black and brown people — share common ground confronting and subverting colonial powers in our struggle for life and justice. There has always been resistance to all forms of oppression, as we know in our bones that there have also always been disabled people visioning a world where we flourish, a world that values and celebrates us in all our beauty.”

Adapted from: Disability Justice - a working draft by Patty Berne — Sins Invalid

Disability Justice: The Next Stage in Movement Evolution

A disability justice framework understands that:

- All bodies are unique and essential.
- All bodies have strengths and needs that must be met.
- We are powerful, not despite the complexities of our bodies, but because of them.
- All bodies are confined by ability, race, gender, sexuality, class, nation state, religion, and more, and we cannot separate them.

Adapted from: <https://sinsinvalid.org/news-1/2020/6/16/what-is-disability-justice>

Disability Justice: The Next Stage in Movement Evolution

- Disability Rights is based in a single-issue identity, focusing exclusively on disability at the expense of other intersections of race, gender, sexuality, age, immigration status, religion, etc.
- Its leadership has historically centered white experiences and doesn't address the ways white disabled people can still wield privilege.
- It centers people with mobility impairments, marginalizing other types of disability and/or impairment.

Adapted from: <https://sinsinvalid.org/news-1/2020/6/16/what-is-disability-justice>

Disability Justice: The Next Stage in Movement Evolution

- At its core, the Disability Rights framework centers people who can achieve status, power and access through a legal or rights-based framework, which we know is not possible for many disabled people, or appropriate for all situations.
- The political strategy of the Disability Rights Movement relied on litigation and the establishment of a disability bureaucratic sector at the expense of developing a broad-based popular movement. Popular movements often begin when people develop political consciousness and name their experiences.

Adapted from: <https://sinsinvalid.org/news-1/2020/6/16/what-is-disability-justice>

Disability Justice: The Next Stage in Movement Evolution

Rights-based strategies often address the symptoms of inequity but not the root. The root of disability oppression is ableism, and we must work to understand it, combat it, and create alternative practices rooted in justice.

Adapted from:

<https://sinsinvalid.org/news-1/2020/6/16/what-is-disability-justice>

Ableism: A Working Definition

A system of assigning value to people's bodies and minds based on societally constructed ideas of normalcy, productivity, desirability, intelligence, excellence, and fitness. These constructed ideas are deeply rooted in eugenics, anti-Blackness, misogyny, colonialism, imperialism, and capitalism.

This systemic oppression leads to people and society determining people's value based on their culture, age, language, appearance, religion, birth or living place, "health/wellness", and/or their ability to satisfactorily re/produce, "excel" and "behave".

You do not have to be disabled to experience ableism.

Source: <https://www.talilalewis.com/blog/working-definition-of-ableism-january-2022-update>

Disability Justice for Indigenous Peoples

- A prevailing view of disability permeates all sectors and erases the rich knowledges about disability from diverse communities around the world.
- We must remember that Indigenous peoples are still impacted by the history of forced assimilation through colonialism and capitalism. This history has shaped our collective adoption of wider social narratives of what disability is within our own Native communities. However, although assimilation has profound impacts on our understandings of disability, our ancestral knowledges are not lost.
- Ancestral stories of disability are found in our land-based knowledge systems, our oral histories, in our art, and within our songs and prayers. They are kept safe within our ancestors' careful planning and refusal to let these important teachings perish. These stories carry our language and customs that shape our worldview as a distinct people.

Source: <https://disabilityvisibilityproject.com/2023/06/18/indigeneity-and-disability-the-teachings-of-our-ancestors-and-being-in-relation-towards-harmonious-outcomes/>

Disability Justice for Indigenous Peoples

- Disability Justice has opened pathways to explore these depths of radical love by holding space for the socio-political and historical positionality of Indigenous communities', and our ancestral knowledges of disability.
- As a people, we are still fighting for visibility and the right for our stories to be held with care within their own right. Because of this, Disability Justice can support aspirations for Indigenous liberation. It is a space to re-write the narratives of disability grown from Indigenous ancestral wisdom for the futurity of disabled relations, Indigenous lands, languages and generations to come.

Source: <https://disabilityvisibilityproject.com/2023/06/18/indigeneity-and-disability-the-teachings-of-our-ancestors-and-being-in-relation-towards-harmonious-outcomes/>

Health Equity and Disparities

- Health equity is the state in which everyone has a fair and just opportunity to attain their highest level of health.
- Health disparities are preventable differences that populations experience in the burden of disease, injury, violence, or opportunities. When people have limited access to resources they need to be healthy, they are more likely to experience health issues.

Source: <https://www.cdc.gov/health-equity/what-is/index.html>

Health Equity and Disparities

- Health is more than a measure of vital signs or absence of disease. Health requires access to clean drinking water and affordable healthcare. Health requires communities with well-funded schools and parks instead of polluted air and toxic waste dumps. Health also comes from access to safe and affordable homes in neighborhoods where people have opportunities to move up economically.
- Health reflects the ways policies shape neighborhoods and support families. For too long, our social practices, laws, and policies have placed more value on some lives than others based on race, class, and other factors.
- We all have dreams for ourselves and our families. But we don't all have the same opportunities to make those dreams come true. Structural racism embedded in every aspect of society is the root cause of the health disparities that persist today.

Source: <https://www.rwjf.org/en/our-vision/why-health-equity.html>

Health Disparities: Indigenous Peoples

- Disparities in health have existed among American Indian and Alaska Native populations since the time of first contact 500 years ago, and they continue to occur across a broad spectrum of disease categories and for all ages.
- American Indian and Alaska Native people today represent roughly 1.5% of the total U.S. population. Relative to the general U.S. population, it is a young and growing population, with one-third of people younger than 18 years and fertility rates that exceed those of other groups.
- More than one-quarter of the American Indian and Alaska Native population is living in poverty, a rate that is more than double that of the general population and one that is even greater for certain tribal groups.

Source: <https://pmc.ncbi.nlm.nih.gov/articles/PMC2567901/>

Health Disparities: Indigenous Peoples

- According to the World Health Organization (WHO), social determinants of health are the “conditions in which people are born, grow, work, live and age, and the wider set of forces and systems shaping the conditions of daily life. These include economic policies and systems, development agendas, social norms, social policies and political systems”.
- Discourse about the social determinants of Indigenous health is not new. In fact, among Indigenous Peoples, it is centuries old. Since the early days of colonialism, Indigenous Peoples have been proclaiming the health harming effects of oppressive political, economic, and social structures and systems.

Source:

[https://www.nccih.ca/Publications/Lists/Publications/Attachments/10373/Health Inequalities EN Web 2022-04-26.pdf](https://www.nccih.ca/Publications/Lists/Publications/Attachments/10373/Health%20Inequalities%20EN%20Web%202022-04-26.pdf)

Health Disparities: Indigenous Peoples

- Social determinants of health are responsible for health inequities, particularly between people of different social and economic positions. For example, it has been widely acknowledged that social determinants account for 30-55% of health outcomes – much more than lifestyle activities such as diet and exercise (WHO, 2021).
- Research has also demonstrated that systems of education, justice, and social welfare contribute more to health outcomes than the health care system (Ruger, 2010; Schillinger et al., 2006; WHO, 2021).
- Indigenous individuals, families, communities, and nations experiencing inequities in the social determinants of health are more likely to carry an additional burden of ill health as well as be restricted from access to resources that might ameliorate these concerns.

Source:

https://www.nccih.ca/Publications/Lists/Publications/Attachments/10373/Health_Inequalities_EN_Web_2022-04-26.pdf

Health Disparities: Indigenous Peoples

- The American Indian and Alaska Native people have long experienced lower health status when compared with other Americans. Lower life expectancy and the disproportionate disease burden exist perhaps because of inadequate education, disproportionate poverty, discrimination in the delivery of health services, and cultural differences. These are broad quality of life issues rooted in economic adversity and poor social conditions.
- American Indians and Alaska Natives born today have a life expectancy that is 5.5 years less than the U.S. all races population (73.0 years to 78.5 years, respectively).

Source: <https://www.ihs.gov/newsroom/factsheets/disparities/>

Health Disparities: Indigenous Peoples

- American Indians and Alaska Natives continue to die at higher rates than other Americans in many categories, including chronic liver disease and cirrhosis, diabetes mellitus, unintentional injuries, assault/homicide, intentional self-harm/suicide, and chronic lower respiratory diseases.
- Given the higher health status enjoyed by most Americans, the lingering health disparities of American Indians and Alaska Natives are troubling. In trying to account for the disparities, health care experts, policymakers, and tribal leaders are looking at many factors that impact upon the health of Indian people, including the adequacy of funding for the Indian health care delivery system.

Source: <https://www.ihs.gov/newsroom/factsheets/disparities/>

Health Disparities: Indigenous Peoples

- American Indian and Alaska Native communities today live with a legacy of cultural trauma as a result of centuries of dispossession at the hands of the U.S. government and its policies and practices intentionally designed to break apart culture, communities, family, and identity.
- Despite this legacy and its arguable effects on life in American Indian and Alaska Native communities today, one need only hear a conversation in Towa between a Pueblo grandmother and her grandchild, visit a summer sheep camp among the Navajo, or attend a Lakota sundance to know that American Indian and Alaska Native culture has endured.

Source: <https://pmc.ncbi.nlm.nih.gov/articles/PMC2567901/>

Health Disparities: Indigenous Peoples

- The time to move beyond documenting health disparities for American Indian and Alaska Native communities to designing and implementing effective culturally informed intervention has long since arrived.
- American Indian and Alaska Native communities have been increasingly frustrated by research that serves simply to document problems that they have long known to exist. At the same time, they are reluctant to accept interventions derived from other's experiences that do not consider their unique social and cultural contexts.

Source: <https://pmc.ncbi.nlm.nih.gov/articles/PMC2567901/>

Health Disparities: Indigenous Peoples

- Discussions of Indigenous health must acknowledge the diversity of Indigenous nations, cultures, languages and traditions.
- It is important to note that colonization is not a singular, historical event, but a persistent and complex constellation of intersecting environments, systems, and processes intended to entrench social, political, and economic determinants that benefit white settler societies, often to the detriment of Indigenous lands, waters, cultures, communities, families, and individuals.
- Since contact, racist and oppressive colonial structures and systems have not only harmed Indigenous Peoples, but the impact of that harm is often passed on through what is referred to as intergenerational trauma (Clarmont & Clarmont, 2016; Cowan, 2020; Methot, 2019; O'Neill et al., 2016).

Source: [https://www.nccih.ca/Publications/Lists/Publications/Attachments/10373/Health Inequalities EN Web 2022-04-26.pdf](https://www.nccih.ca/Publications/Lists/Publications/Attachments/10373/Health%20Inequalities%20EN%20Web%202022-04-26.pdf)

Health Disparities: Indigenous Peoples

- Anti-Indigenous racism and social exclusion have not only resulted in the inequitable distribution of resources, power, and autonomy, they have created barriers to Indigenous people's participation in all aspects of political, economic, and social life (Allan & Smylie, 2015; Das Gupta, 2018; Moreton-Robinson, 2015; Paradies, 2016; Perry & McCallum, 2018).
- Relegated to the bottom of a socially constructed racial hierarchy, after 400 years, Indigenous people continue to experience inequitable social determinants, which directly and indirectly increase their exposure to illness and reduce their capacity to address social determinants of health.

Source:

[https://www.nccih.ca/Publications/Lists/Publications/Attachments/10373/Health Inequalities EN Web 2022-04-26.pdf](https://www.nccih.ca/Publications/Lists/Publications/Attachments/10373/Health_Inequalities_EN_Web_2022-04-26.pdf)

Health and Tribal Elders

- There are over 300,000 American Indian and Alaska Native older adults ages 65 and older in the United States. Tribal elders live in all areas of the country—on tribal lands, urban areas, and rural communities—with the highest rates concentrated in Alaska, Arizona, California, Oklahoma, and New Mexico. Tribal elders are generally revered as knowledge-keepers in their communities, but their communities are extremely diverse in their culture, history, language, and traditions.
- As a result of historical and ongoing harms, tribal elders face significant inequities in terms of access to and outcomes in health care, housing, nutrition, transportation, and other services necessary to aging with dignity. The Older Americans Act (OAA) is one federal vehicle that aims to address the unmet needs of tribal elders and fosters their ability to live independently in their communities. Aging service providers and advocates can better support tribal elders in their communities by understanding the landscape of services available under the Older Americans Act and facilitating connections with older adult-focused tribal organizations.

Source: <https://justiceinaging.org/supporting-tribal-elders-through-the-older-americans-act/>

Health and Tribal Elders

- Title VI of the OAA specifically provides authorization for nutrition, supportive, and caregiver support services grants for older Native Americans. There are 290 grants awarded to organizations representing over 400 American Indian, Alaska Native, and Native Hawaiian communities.
- As of 2021, more than 237,000 tribal elders were served by Title VI programs. Importantly, Title VI programs primarily serve tribal elders in rural, remote, or frontier areas, where distance and transportation barriers otherwise hinder elders' ability to access critical services.

Source: <https://justiceinaging.org/supporting-tribal-elders-through-the-older-americans-act/>

Health and Tribal Elders

- Some of the services offered by Title VI programs include home delivered and congregate meals, and food pantries; cultural events; transportation; and medical services, such as vaccinations, blood sugar checks, diabetes management, assistance devices, and mental health services.
- Such services—some of which are funded with a combination of Title VI and other funding sources—are key to bridging the many inequities tribal elders experience.
- For example, approximately one quarter of all American Indian and Alaskan Native people experience food insecurity, and this inequity is even greater for those in rural communities and was exacerbated during the Covid-19 pandemic.

Source: <https://justiceinaging.org/supporting-tribal-elders-through-the-older-americans-act/>

Health and Tribal Elders

- Title VI programs are using their meal programs to do more than just nourish tribal elders, but also to uplift traditional Native foods, providing a place for elders to share their family recipes, and inviting elders to participate in community gardens.
- These meal programs—much like Title VI social and cultural programs—uplift indigenous traditions and support the survival of American Indian and Alaskan Native people and cultures, which face cultural, historical, and linguistic extinction due to a history of oppression.
- Title VI programs across the country are making significant impacts in their communities. However, they still face barriers in terms of staffing shortages (particularly, in terms of recruiting culturally responsive staff), technical assistance and training needs, and significant budget shortages. Older adult advocates, such as legal aid programs and Area Agencies on Aging, can support tribal elders in their service area by learning about local Title VI programs and their offerings in order to build partnerships, make referrals, and support policy development.

Source: <https://justiceinaging.org/supporting-tribal-elders-through-the-older-americans-act/>

Wrap Up

- Thoughts?
- Questions?
- Comments?

Thank you for your presence
and participation!



Contact Us

Mellie Adu, Arizona Statewide
Independent Living Council
(AZSILC): mellie@azsilc.org;
<https://azsilc.org/>

Melanie Mills, The Arc of
Arizona: Mills@TheArc.org;
<https://arcarizona.org/>

Kara Thrasher, Arizona Statewide
Independent Living Council (AZSILC):
kara@azsilc.org; <https://azsilc.org/>

Eileen Tohonnie, Assist to Independence
and AZSILC: etohonnie@assistti.org;
<https://assistti.org/>

