Disability Decolonized: Indigenous Peoples Enacting Self-determination

Nathan J. Rabang  
*University of Alaska Anchorage, Center for Human Development*

Amy E. West  
*University of Southern California, Keck School of Medicine*

Eric Kurtz  
*University of South Dakota, Sanford School of Medicine*

Jim Warne  
*University of South Dakota, Sanford School of Medicine, Oyáté Circle*

Vanessa Y. Hiratsuka  
*University of Alaska Anchorage, Center for Human Development*

Follow this and additional works at: [https://digitalcommons.usu.edu/ddnj](https://digitalcommons.usu.edu/ddnj)

Part of the Disability Law Commons, Disability Studies Commons, and the Social Policy Commons

Recommended Citation

Available at: [https://digitalcommons.usu.edu/ddnj/vol3/iss1/11](https://digitalcommons.usu.edu/ddnj/vol3/iss1/11)
Disability Decolonized: Indigenous Peoples Enacting Self-Determination

Nathan J. Rabang,1 Amy E. West,2 Eric Kurtz,3 Jim Warne,3 and Vanessa Y. Hiratsuka1
1University of Alaska Anchorage, Center for Human Development, Anchorage, AK
2University of Southern California, Keck School of Medicine, Los Angeles, CA
3University of South Dakota, Sanford School of Medicine, Vermillion, SD

Plain Language Summary

The phrase “nothing about us without us” is a saying used by people who demand to be part of things instead of only end users. This paper is about groups of people that often have things like policies and programs made for them but not by them—Indigenous peoples and people with disabilities. They have similar experiences being taken advantage of by dominant culture. We also write about the idea of self-determination. Self-determination is the ability for a person or a nation to set goals themselves and have the proper information and tools to reach those goals. We hope to show that true diversity, equity, and inclusion (DEI) is possible for these communities, and we give examples of programs that help individuals reach their goals.

Abstract

Populations researched often have little if any input in the means of data collection, analysis, or authorship of the findings published. They are excluded from participating in the scientific methods even though they are the subject of the content that is being produced. This is true for Indigenous populations and the disability community around the globe. Researchers usually use colonial methodology that does not encompass the values of these communities or have their well-being in mind. This paper examines the history of colonization and how it has infiltrated science and inhibits self-determination of Indigenous peoples. Indigenous communities need to have the means and power for self-determination. For individuals with disabilities, this includes rights to services and programs that give the respect and person-centered care they deserve to make informed decisions about their lives. Moreover, there is a recognized need for culturally appropriate services that empower American Indian and Alaska Native (AI/AN) people with disabilities to lead independent lives in their own communities—urban or rural. AI/AN cultures may view disabilities differently than those in the mainstream U.S. Barriers and challenges for AI/AN individuals with intellectual and developmental disabilities (IDD) and AI/AN families of individuals with IDD in access to services include inadequate funding, personnel shortages, housing shortages, lack of coordination among agencies, lack of consultation with tribes, and problems identifying persons eligible for services. AI/AN-specific programs that have begun to bridge the gap in access to and development of culturally competent services.
services such as Oyáte Circle and development of collegiate courses focused on AI/AN disabilities issues. There remains a need for partnership with AI/AN tribes for disability services and incorporation of AI/AN people with disabilities as equitable partners in program development and implementation. To reach a full decolonization of IDD health care and fully embrace diversity, equity, and inclusion (DEI) principles, individuals in these communities need to be viewed as experts in their journey of resilience.

Introduction

Indigenous peoples are engaging in the process of decolonization as they seek reconciliation and exercise resilience in the face of a colonial legacy (e.g., historical and current processes of oppression, disenfranchisement, attempts at genocide, deculturalization through education and religion, etc.; Cross et al., 2019; Smith, 2022). Likewise, individuals with disabilities are in the midst of a self-advocacy movement, seeking reconciliation and exercise resilience from an ableist legacy (e.g., historical and current processes of oppression, disenfranchisement, attempts at genocide, lack of access to education, etc.; Charlton, 1998; Goodley, 2005). Policymakers; education, human services, and health program personnel; academics; and community members must become aware of the legacies of colonialism and ableism to support the decolonization of disability services and programs, particularly if advances are to be made with a focus on diversity, equity, and inclusion (DEI; Crimmins et al., 2019; Meekosha, 2011).

In this article, we summarize decolonization efforts in the U.S., with particular attention to the intersection with disabilities self-determination policy and discuss Indigenous disability programs that exemplify the “not about us, without us” concept. This paper also addresses similarities between disability and Indigenous cultures and legislative impacts that support empowerment and inclusion for Tribal members with disabilities throughout the nation. American Indian and Alaska Native (AI/AN) people have a unique relationship with the Federal government, as described in Article I, Section 8 of the U.S. Constitution and affirmed through treaties, federal law, Supreme Court decisions, and executive orders (Kruse et al., 2022). This relationship provides the basis for Federally provided forms of health care, education, and sustenance to AI/AN peoples in perpetuity (Kruse et al., 2022). We use the terms Indigenous, AI/AN intentionally as each term has a nuance of meaning that has political, social, and legal significance.

For true movement to occur from nondiverse to diversity, inequity to equity, and exclusion to inclusion, DEI work must reckon with history. Within Indigenous populations, it is essential to have knowledge of colonial history and the ongoing expressions of colonial viewpoints. Indigenous populations are diverse. There are 574 federally recognized tribes in the U.S. and more than 100 state-recognized tribes—each with a history and culture of their own. Justice and reparations are inclusive of honoring Indigenous ways of knowing, Indigenous values, and repatriation of resources and are the first steps to healing from the historical damage inflicted upon AI/AN peoples. Performative DEI such as professional organization adoption of DEI statements or token additions of Indigenous disabled collaborators to leadership groups without fundamental change in resources and power is not useful DEI. Finally, for DEI to be
transformative, it must be (1) grounded in praxis—welcoming and implementing ways of being that support and enhance decolonized programs; and (2) incorporate systemically through policies and measurable actions that support Indigenous ways of living, knowing, and being.

Self-determination is empowerment of marginalized populations to have the same rights and inclusion as anyone else in society. Self-determination is a concept that is strong within both the AI/AN political and legislative discourse, within the intellectual and developmental disability (IDD) community, as well as other disability communities (Charlton, 1998; Clinebell & Thomson, 1978; Kruse et al., 2022). Self-determination in disability communities can be interpreted as individuals with disabilities making one’s own decisions and choosing and setting personal, educational, and professional goals through self-advocating and empowerment (Charlton, 1998; Goodley, 2005). This also includes the right to make one’s own medical decisions. Within the AI/AN context, self-determination is defined as the movement by which Tribal Nations, by exercising their sovereignty, seek to achieve restoration of Tribal communities, self-government, cultural renewal, land development, educational control, and equal or controlling input into federal government decisions concerning AI/AN policies and programs (Carroll et al., 2022; Clinebell & Thomson, 1978; Tsosie, 2001). Tribal Nations are referenced in the U.S. Constitution and have sovereign rights as nations (Declaration of Independence, 1776; see also Carroll et al., 2022; Clinebell & Thomson, 1978; Tsosie, 2001).

**Position Statement**

While self-determination and agency are essential for these communities, both individually and collectively, inequitable practices have stifled the exercise of self-determination, especially when there is intersectionality between the lived experience of disability and AI/AN culture. Given the importance of inclusion, a description of the positionality of authors is a necessity for assessing the validity of the content, conclusions, and implications for marginalized or colonized communities (i.e., nothing about us without us; Charlton, 1998; Lock et al., 2022; Tuck, 2009). Many of the co-authors are Tribal Members and have individuals with a disability. Through personal experience with marginalization and exclusion, this article will allow for personal experiential “storytelling,” which is an Indigenous model for communication, education, and intervention. The first author, Nathan Rabang, is an enrolled member of the Shxwhá:y Village in Canada, an Indigenous evaluator and researcher in a University Center for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD). Amy West is Southern Cheyenne, a Clinical Psychologist, a Professor at the Keck School of Medicine at the University of Southern California (USC) and Children’s Hospital Los Angeles and affiliated with the USC UCEDD, and an Indigenous researcher whose work focuses on intervention development to address mental health and substance use disparities in AI/AN communities. Eric Kurtz is the executive director of the UCEDD at the University of South Dakota Sanford School of Medicine, associate professor of pediatrics, and a developmental psychologist who has spent his career working toward improving equity, inclusion, and quality of care across health, education, and human services in Indigenous, rural, and frontier areas. Jim Warne is an enrolled member of the Oglala Lakota (Sioux) Nation, an Emmy nominated filmmaker, Indigenous educator and advocate. Jim
Warne is a disability scholar includes developing “Indigenized” disability programs at San Diego State University, Interwork Institute (1993-2015), University of South Dakota Sanford School of Medicine UCEDD (2017) and the Native Disability Center at the Sonoran Center for Disability Arizona College of Medicine UCEDD (2021). The senior author, Vanessa Hiratsuka is an enrolled member of the Navajo Nation and descended from the Winnemem Wintu in the U.S., an Indigenous public health scholar and bioethicist and assistant professor/co-director of research and evaluation for a UCEDD with health-related disabilities.

AI/AN Historical Background/Effects of Colonization and Health Disparities

AI/AN people experience some of the highest rates of disabilities in the U.S. yet are subjected to among the most profound social inequities with respect to health determinants and services (Kruse et al., 2022; Sequist, 2021). National surveillance data show that 3 of every 10 people from the AI/AN population report having a disability (Courtney-Long et al., 2017). Additionally, many AI/AN people with disabilities are either undiagnosed, unserved, or underserved (Section 21 of the Rehabilitation Act). Almost 80% of the AI/AN population resides outside of reservation/land trusts and about 40% reside in rural areas (Kruse et al., 2022). The disability culture(s) and AI/AN culture(s) have many similar experiences related to disparities in service and inappropriate services and approach(s). To understand the lack of services and more importantly, the lack of culturally appropriate services, one needs to study the cultural identity within Indigenous groups and the systemic disenfranchisement implemented by settler governments that hinders individuals from the care and services they need. Furthermore, examining the history and current methods in place that aid tribal members with IDD is another dimension to this story worthy of attention.

Self-Determination in AI/AN Law/Disabilities Law

Indigenous peoples were displaced and endured acts of genocide via the doctrine of manifest destiny, and colonization via European country exchanges of Indigenous lands such as the Louisiana Purchase or the Oregon Treaty, treaties with Mexico, and annexation of the Texas Republic. The sovereignty of Native nations was continually unrecognized, resulting in displacement and military-enforced relocation of Indigenous peoples from ancestral lands to reservations. The Dawes Act of 1887 broke up promised land to American Indians into individual allotments in hope to assimilate Indigenous people into Western farmer culture. The separation of Indigenous peoples from their land base had the intended outcome of undermining the autonomy of tribal nations, and associated disruptions to Indigenous peoples’ relational and collectivist orientations (Cross et al., 2019; Tsosie, 2001). The traumatic effects of all these attacks on Indigenous populations have been sustained over time and are reflected in the current climate of how America sees and treats its Indigenous peoples (Kruse et al., 2022).

The repercussions of stolen land, historic trauma, a social climate of racism and racial discrimination are seen in the contemporary disparities in social determinants of health and poor health status. AI/AN people compared to the overall U.S. population have a high rate of poverty
(26% vs 14%), lack of access to complete plumbing (5.8% vs 0.3%), live in housing conditions that are overcrowded or have other structural issues (34% vs 7%), lack a high school education or equivalent (20% vs 12%), and lack a full-time worker in the family (30% vs 16%; Sequist, 2021). AI/AN people are more likely to have poor access to adequate health and educational services and are seen on AI reservations, in AN villages, and in urban centers (Christensen & Damon, 2022).

Inequities experienced by AI/AN people have caused health disparities and intergenerational trauma that negatively impacts AI/AN people throughout the life course (Black et al., 2015; Cohen et al., 2011; Marshall & Largo, 1999). AI/AN people have socially acquired disabilities as results of colonialism (Black et al., 2015; Christensen & Damon, 2022; Huyser et al., 2021; Kruse et al., 2022; Marshall & Largo, 1999). Health disparities and health inequity create social situations resulting in higher rates of interpersonal violence, intentional injury, depression, anxiety, high rates of substance misuse, and suicide as well as manifestation of higher rates of chronic diseases including diabetes, asthma, and cardiovascular disorders (Christensen & Damon, 2022). One of the few needs assessments on AI/AN developmental disabilities found that issues of poverty, drug and alcohol misuse, mental health, and lack of jobs in many AI/AN communities make it more difficult for people with developmental disabilities to live inclusive community lives (Cohen et al., 2011). It should be framed, however, that these are manifestations of historical systemic failures. Indigenous scholar Eve Tuck has noted the "damage-centered narratives" placed upon AI/AN communities that are so often decontextualized, failing to account for the centuries of "occupation of Native lands, genocide, and colonization" (Tuck, 2009, p. 415).

Self-Determination Explained

The Indian Civil Rights Act was implemented in 1968. President Lyndon Johnson called for “termination” to be replaced by Indian “self-determination.” Congress passed the Indian Civil Rights Act “to ensure that the American Indian is afforded the broad constitutional rights secured to other Americans...[in order to] protect individual Indians from arbitrary and unjust actions of tribal governments” (Pevar, 1992). The Indian Civil Rights Act allows for federal intervention and access to sovereign Tribal Nations legal process. It is controversial as it allows federal intervention in legal disputes and interferes with sovereignty. For instance, the Americans with Disabilities Act (ADA) is not required for sovereign Tribal Nations to incorporate into Tribal Nation law(s), It is up to each individual Tribal Nation to incorporate some or all of the ADA legislation.

Self-determination on an individual level is the empowerment and right to choose the future outcomes for oneself. Self-determination on a personal level can range from being able to choose what time to eat a meal to what type of care an individual wants to pursue. Individuals with IDD deserve the same dignity and respect as every citizen. People with disabilities should be afforded the freedom to have self-directed living and the freedom to learn from one’s own experiences (i.e., the dignity of risk; McNeese & Myhill, 2014; Perske, 1972).

In a community, self-determination is the right to determine their own destiny. Examples of self-determination for a Native Nation entails the rights and entitlements to choose how to
use its land and how to care for its citizens. This includes how and when to implement laws. Tribal nations are sovereign states that legally have the same rights and dignity as a foreign government (Clinebell & Thomson, 1978; Tsosie, 2001).

Tribal members who are also individuals with lived experience with IDD often have low to no access to cultural and linguistically competent services. This started to change in 1964 and continued until 1990. However, the tribal and IDD communities continue to face contention. In 1964, the Civil Rights Act was passed in the U.S. This made it illegal to discriminate on the basis of race, color, religion, sex, or national origin. This drastically changed the climate of the U.S. With the passage of this act, segregation was prohibited across the country, including segregating and discriminating against Indigenous peoples. In 1990, the ADA was passed. This made it illegal to discriminate against people with disabilities. It also required employers to provide reasonable accommodations to employees with disabilities. With these new laws in place, the outlook of tribes and the disabled community should be clear and prosperous. However, just because these laws have been enacted, it does not mean these communities are safe from colonial violence and systemic marginalization.

Intersections of Self-Determination

Although these policies are steps in the right direction, they are not sufficient for decolonization and to address an ableist society. True self-determination for AI/AN people is not possible without full tribal sovereignty. For the AI/AN disabled community, self-determination is not possible without addressing ableist discrimination and colonization. This includes, having decision-making input in what types of care they receive, who gives them the care, and what community-based services are right for them. Additionally, AI/AN self-determination looks like self-government with no federal oversight, language and cultural renewal, land development, educational control, and equal or controlling input into federal decisions concerning AI/AN policies. Another layer on the way to true self-determination was the Indian Self-Determination and Education Assistance Act (ISDEAA) signed into law in 1975.

Before the ISDEAA, there were two typical routes in which Indigenous children received an education. The first was missionary education and the second was U.S. AI/AN boarding schools, also known as residential schools in Canada. The U.S. Interior Department released a first-of-its-kind federal study of Native American boarding schools that for over a century sought to assimilate Indigenous children into White society (Newland, 2022). The report notes that between 1819 and 1969, the Federal Indian boarding school system consisted of 408 Federal schools across 37 states or then-territories, including 21 schools in Alaska and 7 schools in Hawaii (Newland, 2022). The initial analysis presented in the report noted that approximately 19 Federal Indian boarding schools of the 408 accounted for over 500 American Indian, Alaska Native, and Native Hawaiian child deaths (Newland, 2022). Education of AI/AN students created and perpetuated acts of cultural genocide as school children were given White names and forced to speak English. AI/AN students were banned from practicing their culture and punished for speaking their Indigenous languages. School systems, staff, and educational practices were intentional and deliberate in their attempts to destroy Indigenous peoples’ culture and
traditional way of life. The ISDEAA stepped in as a broad means to separate church and state and shut down many of the missionary schools. Although this changed the landscape of the American Indian education system, the last residential school in Canada was finally closed in 1996 (University of Ontario Indians, 2013). AI/AN families are currently impacted by the historic trauma from this educational system, negatively impacting Indigenous peoples’ trust in educational settings and the intentions of educators.

Jim Warne produced the award-winning film “Remember the Children,” which features elders who are survivors of the U.S. Indian boarding schools. His mother, Beverly Stabber Warne, attended the Pine Ridge Boarding School in the 1940s and is featured in the film. Thousands of children died of abuse and neglect at the boarding schools, many left in unmarked graves. Now they are being found and identified. Historical and intergenerational trauma are associated with current health disparities and significant disability rates for Tribal members.

Ending the inhumane treatment of children in these schools was a turning point in Indigenous educational rights. However, ISDEAA did more than just end institutionalized cultural genocide. The ISDEAA created the means to apply to federal grants from the Department of Education that could be awarded to the tribe itself to create culturally appropriate school curricula for AI/AN people. Creating a new education system from scratch is a massive feat for any nation—especially when barriers are still present in getting funds, finding and training teachers, and recovering from the cruelty of residential schools. In enacting the ISDEAA, the climate of AI/AN education shifted. The tribal control of school systems allowed for incorporation of practices and values such as self-sufficiency, tribal identity, Indigenous forms of communication and language, cultural traditions, and incorporation of restorative practices in discipline. In addition, the community building of creating appropriate curriculums that are individualized for each tribe cannot be understated. There is not one approach to Indian Country in the U.S. Each Tribal Nation has their own language, culture, and sovereign governmental structures.

Despite the hurdles that still stood in the road of fair and equal education, Tribal Nations could now teach things along the lines of language revitalization, traditional arts, and culturally significant ceremonies and rituals. Previous paternalistic federal policies, including termination and relocation efforts of the 1950s and 1960s, were no longer the law of the land and several Tribes regained land and sovereign governmental rights.

**Individual Self-Determination in Practice**

The 1990 reauthorization of the Individuals with Disabilities Education Act (IDEA, 2004) was another federal act addressing self-determination of a marginalized population, which further strengthened youth transition services based on student needs and focused their interests and preferences. IDEA created the Individualized Education Program (IEP). An IEP is a legal document that dictates the education journey of an individual with IDD. It is agreed upon by a team that consists of the parents of the child and school district personnel (usually, people from the special education department and/or the child’s classroom teacher). This individualized
approach to education is one way that all students across the country can gain an education that is tailored specifically for them.

On a national level, for public schools across the country, IEPs are valuable to create the best learning environment for students. However, this is not entirely the case for AI/AN students. Culturally appropriate services are needed in the classroom as well. AI/AN people have a relational and collectivist orientation (Cross et al., 2019). Participation in cultural activities and community living is essential in Indigenous worldviews to achieve a good quality of life and maintain health (Black et al., 2015; Cohen et al., 2011; Cross et al., 2019; Fuentes & Lent, 2019).

There is a recognized need for culturally appropriate services that empower AI/AN people with disabilities to lead independent lives in their own communities, be it in urban or rural areas, on reservations, rancherias, or villages. AI/AN cultures may view disabilities differently than those in non-AI/AN populations. There are over 200 Indigenous languages still spoken today. Barriers and challenges for AI/AN individuals with IDDs and AI/AN families of individuals with IDD access to services include inadequate funding, personnel shortages, housing shortages, lack of coordination among agencies, lack of consultation with tribes, and problems identifying persons eligible for services.

**Self-Determination and Culturally Appropriate Settings**

There are several AI/AN-specific programs within the UCEDD network that have begun to bridge the gap in access to and development of culturally competent services such as Vocational Rehabilitation Services Projects for American Indians with Disabilities, inclusion of AI/AN tribes and advocates in state and national policy development, and tribe-specific interventions. However, the need for culturally congruent programs have always been necessary.

A study in 1999 confirmed a high need for expanding home-based services, community awareness programs, local outreach efforts, and professional staff development (Ma et al., 1999). A program in the U.S. was developed at the University of South Dakota called Oyáte Circle, which helps the AI/AN disability community to connect with much needed services and care. The Oyáte Circle addresses a culture first approach to disability services for Tribal nations in South Dakota. Continued development of collegiate courses focused on AI/AN disability issues are developed and efforts continue for creation and implementation. Because of extreme poverty and rural access challenges, there remains a need for states to partner with AI/AN tribes for disability services and incorporate AI/AN people with disabilities as equitable partners in program development and implementation (Black et al., 2015). This conclusion is similar to the findings in 1999. Culturally competent programs take time to develop and implement (Ma et al., 1999). Building these programs from the ground up and hiring appropriate staff takes time, leadership, funds, and recognition.

To ensure a true statewide approach, the Center for Disabilities at the University of South Dakota Sanford School of Medicine developed the Oyáte Circle. In the Lakota language, Oyáte is translated to “the people.” The Oyáte Circle is focused on the largest community of color in South
Dakota, where Tribal members represent nearly 10% of the state’s population. The Oyáte Circle is a resource, education, outreach, and training program that serves all nine tribes in South Dakota. Through the Oyáte Circle, SD UCEDD has continued its community engagement and presence in tribal communities and events across South Dakota. Utilizing the universal approach, the Oyáte Circle adapts the content to be applied to other underserved populations. All resources use the Oyáte Circle’s own logo, language, graphics, and color schemes. These elements are culturally appropriate and use Native communities’ language and terminology (e.g., the term “disability” does not exist in the Lakota language). Past publications were branded by the University of South Dakota Sanford School of Medicine, but there is a longstanding distrust of institutions, including universities, among AI/AN populations. Program staff note that using Oyáte Circle branding has made a significant difference in how the products are perceived and received by the AI/AN community. This has proven to be a stable resource in maintaining Tribal relations across the organization’s portfolio of work.

One example of the Oyáte Circle’s efforts includes the Advocacy and Leadership Training for Native Americans with Disabilities & Their Families program. In partnership with the South Dakota Council on Developmental Disabilities, Oyáte Circle has developed and implemented advocacy and leadership training along with resources specific to Native Americans with disabilities and their families. The purpose is to raise the expectations of people with disabilities and their families and to increase their ability to communicate, advocate, and lead with others. This initiative has established an advisory group of Native Americans with disabilities and their families to advise and participate in the development and training activities. These efforts continue to provide an ongoing presence and sustainable resource in Indian Country on disability-related issues and needs.

Another Oyáte Circle program has focused on increasing voter registration and turnout among people with disabilities across Indian Country in South Dakota. Oyáte Circle partnered with Disability Rights South Dakota and the South Dakota Developmental Disabilities Network to employ strategies aimed at increasing the ability of people with disabilities to exercise their voting rights, particularly those residing on Tribal lands. This nonpartisan initiative served to inform and educate people with disabilities about the process of participation in the voting process, including voter registration, lists of candidates and issues on the ballot, and where/how to vote. Additional emphasis was placed on addressing particular challenges for Tribal members with disabilities in rural, remote, and reservation communities.

These efforts are also making an impact nationally, through a partnership with the Association of Maternal Child Health Program (AMCHP). Oyáte Circle has developed a Tribal relations community of practice for regional maternal child programs and teams across the states of Colorado, Montana, North Dakota, South Dakota, Utah, and Wyoming. This initiative is increasing in knowledge, skills, and strategies; cultural responsiveness; and engagement with Tribal populations while providing ongoing technical assistance for state teams and follow-up support.

The Oyáte Circle is a perfect example of the intersection of critical Indigenous theory and
disability studies. This program lives in the University of South Dakota’s School of Medicine and is an outreach, training, and education program that helps AI/AN students with disabilities. Oyáte Circle also offers technical support for tribal communities that share information and opportunities available outside of the Oyáte Circle and beyond. In addition, one incredible point to highlight is they hire and train community members to assist in their work. Their Disability Awareness Training Program is funded through the Administration of Community Living and Department of Health and Human Services. The goal is to create a “how-to” handbook for AI/AN communities and service providers that includes how to navigate disability in a culturally appropriate space (Oyáte Circle, 2020). The handbook also has information on tribal college counselors and other professionals who work in the disability community. In 2021, the Oyáte Circle program was awarded the Multicultural Council Award for Leadership Diversity by the Association of University Centers on Disability (AUCD). This recognition is crucial for creating new programs across the country. In 2022, the Oyáte Circle shared their presentation with the Multicultural Council (MCC) of the AUCD network, whose mission is to promote a rich culturally diverse perspective and the disability lived experience. Members in attendance shared how this presentation expanded their understandings of disability and development within the AI/AN community, an example of the value of cross-cultural learning experiences.

With programs like Oyáte Circle getting national recognition for the phenomenal work they do, it is natural for other states to follow suit and provide high-quality services for their communities. The Sonoran Center for Excellence in Disabilities, a UCEDD at the University of Arizona, modeled their new Circle for Indigenous Empowerment on the Oyáte Circle program, and is now a sister program for the Oyáte Circle. This approach has proven to be an effective strategy to gather data, input, needs assessment, comparative analysis, and discussion/listening sessions for inclusion from AI/AN communities and people with disabilities. The Sonoran Center offers community living programs to urban and rural communities, health and wellness programs, transition, and employment services to their AI/AN communities across the state. This is also similar to the Alaska UCEDD as well. The Center for Human Development has programs that include but are not limited to college educational skills, friendship and dating programs, micro enterprising, work incentive assistance, traumatic brain injury services, disability justice, and many other trainings that reach urban and rural communities across the state. Furthermore, each state has their own diverse AI/AN communities with their own specific cultural needs. There is no one-size-fits-all method to creating a universal program. Adapting and changing based on community needs should be at the forefront in the development of creating congruent programs.

Disability is usually defined in the media and Hollywood within the medical model. Hollywood has inappropriately stereotyped Indigenous cultures and disabilities cultures for many years. There are social definitions of disability and cultural definitions that also serve to define individuals with disabilities (Bottema-Beutel et al., 2021; Charlton, 1998; Davis & Sanchez, 2021). Someone with IDD can have a medical diagnosis that dictates what kind of services or treatment they receive (Okoro et al., 2018). However, in a social model of disability, the environment dictates how someone in the IDD community fits in these spaces (Oliver & Barnes, 1998). To explain further, the social model definition of disability does not see the disability as an impairing illness like the medical model (Davis & Sanchez, 2021). In the social model, the interaction of the
body and the space is more important. If there is a disruption between this harmony, the social model defines the environment as the factor that should adapt, not the body of the individual (Bottema-Beutel et al., 2021).

Dissecting these ideas even more, a cultural definition can be harder to articulate. What would disability look like to a community with no centralized schooling or easy access to a doctor? Indigenous education methodology is a vast area that challenges Western notions of academia. For many communal teaching methodologies, learning is done in the family unit and the spaces where child rearing happens. A parent knows their child’s needs better than centralized teachers in a crowded classroom. Family spaces are accommodating and flexible. Who defines disability in these situations? Family units that teach and adapt to fit their child’s educational needs, even in a subsistence lifestyle, have no need for labeling their child with otherness or telling them they have to learn differently than their siblings. An example of this can be found in Alaska’s Special Education Service Agency (SESA).

SESA provides training and support for unique educational needs across Alaska. They offer consultations and services for rural and urban communities. In addition to special education services, SESA offers culturally specific curricula in support of AI/AN IEPs. These resources were developed via a collaborative partnership between Alaska’s UCEDD, Indigenous family members of individuals with IDD lived experience, and community-placed educators. Some examples include, set-net fishing skills and cold-water safety skills, traditional Inupiaq sewing, and introduction to traditional carving (SESA, 2022). Other services offered are financial literacy and self-employment skills. By incorporating traditional teaching styles, focusing on culturally appropriate skill sets, and having community members teach, these Alaska Native curricula incorporate Indigenous forms of education and life skills that are lacking in standard U.S. educational settings.

**Concluding Thoughts**

There is no one approach to serving Tribes and Nations that have many distinct cultural perspectives, languages, geography, and legal classifications (trust lands, Alaska corporations, reservations, Treaty Tribes, Self-Governance Tribes, etc.). The indigenized approach referenced in this article is a small example of the diversity of AI/AN people and diverse approach to disability services. Through self-determination on a community and individual level, AI/AN people with disabilities are shifting power differentials, are being recognized and treated as experts by honoring their lived experiences with policies, programs and practices adhering to culturally consistent concepts of health, wellbeing, and community. The journey to equity is a process of decolonization (Meekosha, 2011). Centering Indigenous peoples’ resistance, resilience and resourcefulness is allowing communities to exercise their sovereignty to move away from a deficit focus and utilize models driven by Indigenous peoples themselves (Came et al., 2019). Socially acquired disabilities from colonialism can be mitigated through decolonization and improvement in quality of life as well as through improved Indigenized disabilities programs and policies.
References


Special Education Service Agency. (2022). Alaska traditional transition skills. [https://sesa.org/resources/educational/alaska-traditional-transition-skills/](https://sesa.org/resources/educational/alaska-traditional-transition-skills/)

