



# **Personal Journeys towards *Hózhó* (Holistic Wellness)**

The Lives of Indigenous Relatives with Disabilities

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*The Diné believe that all living things and creatures live in harmony and reciprocity alongside the physical natural world and the universe.*

The organization of this report aligns with the *Diné* Thinking Process Framework within the *Diné* paradigm, *Sa'ah Naaghái Bik'eh Hózhóón* (SNBH).



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# Executive Summary

The Inter-Tribal Disability Advocacy Council (IDAC) was established in 2023, with the sponsorship of the Native American Disability Law Center (NADLC) and funding from the Borealis Philanthropy, to elevate the voices and experiences of Indigenous Americans with disabilities across the land now known as the United States.<sup>1</sup>

Between July 12 and October 28, 2023, 29 participants from 14 states representing 16 different Indigenous communities participated in nine virtual Talking Circles hosted by the IDAC. The participants primarily identified as either an Indigenous person with a disability or a family member of an Indigenous person with a disability. Because of the level of interest from the advocacy community, the IDAC conducted one virtual Talking Circle for advocates for Indigenous people with disabilities. The participants in all Talking Circles were invited to share the barriers they faced to full and meaningful participation in life, supportive factors and resources, and recommendations for solutions and support.

The layout of this report aligns with the *Diné* Thinking Process Framework within the *Diné* paradigm, *Sa'ah Naaghái Bik'eh Hózhóón* (SNBH). The Diné believes that all living things and creatures live in harmony and reciprocity alongside the physical natural world and the universe. SNHB consists of four cyclical phases: *Nitsáhákees* (Thinking), *Nahat'á* (Planning), *liná* (Action), and *Sihasin* (Reflection).

## ***Primary issues facing Indigenous people with disabilities are:***

- Health Care
- Education
- Employment and Financial Security
- Housing
- Community Engagement
- Independent Living

The IDAC aims to encourage and assist the United States government and national, state, and local organizations to develop meaningful and impactful policies based on the participants lived experiences of Talking Circle.

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<sup>1</sup> The IDAC and this report use the term “Indigenous” to represent the people and communities who lived and continue to live in the country known as the United States prior to the arrival of Europeans.

# Nitsáhákees (Thinking)

## ***Conceptualization and Creation of the Inter-Tribal Disability Advocacy Council***



### **Hoskie's Vision**

The driving force behind the conception of the IDAC was Hoskie Benally, Jr., the Community & Government Liaison for the NADLC in Farmington, New Mexico. He is also a Member of the National Council on Disability (NCD). Mr. Benally is *Diné*, a traditional educator and an individual with a disability. The NADLC is a non-profit legal organization that serves Native Americans with disabilities and their families across the Four Corners Region. The NADLC advocates for the rights of Native Americans with disabilities and enforces, strengthens, and brings harmony to their communities through free individual representation, systemic advocacy, and community education.

Through their work with regional and national task forces and councils, Mr. Benally and the NADLC realized that even the most well-intentioned advocates and supporters are uninformed about the unique legal issues and service delivery challenges facing Native Americans with disabilities. Mr. Benally and the NADLC applied for funding to sponsor the creation of the IDAC to elevate the voices and experiences of Native Americans with disabilities from across the country.

Grounded in his *Diné* cultural identity, Mr. Benally envisioned a project that highlighted participants' raw stories and souls rather than reducing them to data points. This emphasis on honoring people's lived experiences as both Indigenous and Disabled is central throughout the conceptualization and establishment of the IDAC, the planning of the project, the conducting of the Talking Circles, and the reporting of findings.

The IDAC's formation and work are guided by the *Diné* philosophy of life. Mr. Benally and the IDAC recognize that different Indigenous communities have different views of life and their relationship with others and the world; however, the IDAC felt that there are commonalities and consistencies across communities that support using the *Diné* approach.

The *Diné* philosophy of life focuses on *hózhó*, the *Diné* principle of beauty and seeking, establishing, and achieving harmony. It is only through *hózhó* or harmony that the *Diné* can Walk in Beauty Down the Corn Pollen Path. The *Diné* believe that all living things and creatures live in harmony, and this harmony is achieved through *K'é*, which emphasizes maintaining relationships, not just between family, friends, and other humans, but establishing and maintaining reciprocity alongside the physical natural world and the universe. Achieving harmony begins with obtaining internal harmony based on establishing holistic wellness involving spiritual, emotional, mental, and physical healing and acceptance.

Indigenous people with disabilities, including IDAC members, are on personal journeys toward *hózhó*. This journey begins with acceptance of their disabilities and then gaining recognition as individuals with needs and wants. Through their personal journeys toward holistic wellness, they become self-advocates and move toward a positive self-image and sense of self-worth that may not be supported or encouraged by the dominant society. Each IDAC member is working towards internal harmony and is now helping others gain knowledge, wisdom, and truth about who they are so they too can gain internal harmony.

The IDAC's approach to the Talking Circles and to summarizing the information provided by the participants aligns with the *Diné* philosophy of life and the supporting thinking process within the *Diné* paradigm, SNBH. SNBH is the ongoing path toward balance and wellness between all beings. *K'é*, the process of establishing and maintaining relationships, is central to achieving SNBH. This process is achieved through intentional phases of *Nitsáhákees* (Thinking), *Nahat'á* (Planning), *Iiná* (Action), and *Sihasin* (Reflection). For instance, the IDAC thought (*nitsáhákees*) about what they wanted to gain from the Talking Circles, how the information would be requested, and who would be involved. They planned (*nahat'á*) for the Talking Circles by sending out invitations to those who wanted to participate, developed consistent questions and approaches, and organized those who registered to attend. The Talking Circles were then conducted (*iiná*) via zoom meetings. After the Talking Circles, the IDAC reviewed the results (*sihasin*) and adjusted as needed. The Indigenous methodologies used as the approach for this report complement SNBH.

## Creation of the Council

In creating the IDAC, NADLC recruited two consultants and issued a public call for volunteers from Indigenous tribes across the United States. The initial goal was to have at least 60% of the IDAC be Indigenous people with disabilities; ultimately, all members identified as such. Members are disability advocates and subject matter experts with a blend of grassroots and Western academic expertise. Additionally, the NADLC hired Joy Henry as the IDAC Project Coordinator. Henry was selected due to her strong background in research and writing, which she demonstrated as an undergraduate at Northern Arizona University.

### ***Inter-Tribal Disability Advocacy Council Members***

Hoskie Benally, Jr., *Diné*, Community & Government Liaison, Native American Disability Law Center

Dr. Maggie Conners Deforge, OTD, OTR/L, St. Regis Mohawk Tribe *Kanien'kehá:ka*, Chair of Occupational Therapy for Native Americans

Héctor Manuel Ramírez, PhD, Apache, Commissioner, California Commission on Disability, Access & Los Angeles Commission on Disabilities

Jules Edwards, *Anishinaabe*, Co-Founder of Minnesota Autistic Alliance, LEND Fellow, AUCD National Training Directors Council Fellow

GeWaden Dunkley, Bois Forte Band of Chippewa, Staff Attorney Mid-Minnesota Legal Aid: Disability Law Center

### ***Consultants***

Dr. Kimberly Yellow Robe, DHA, MBA, Rosebud Sioux Tribe, Associate Director at Banner University Health

Dr. Darold H. Joseph, PhD, Hopi, Assistant Professor at Northern Arizona University

### ***IDAC Coordinator***

Joy Henry, Diné, IDAC Project Coordinator, Native American Disability Law Center

### ***Graduate Student Assistants from Northern Arizona University***

Brooki R. Beasley

Tanya Nasbah Chischilly

Rae L Tewa

Candi Lynn Running Bear

Nicole Begay

## **Intersectionality**

One purpose of the IDAC is to build community connections. Too often, communities exist in silos – separated by perceived differences, distrust, and distance that can be attributed to a combination of historical, social, economic, and cultural factors. These silos are understandable when there can be inherent risk in providing information. Indigenous people already represent an invisible minority community that has survived because of their culture, strength, and resilience. It is vital to comprehend that the experiences of Indigenous communities are diverse, as there are 574 federally recognized tribes in the United States, each with its unique history and circumstances. However, some common factors contribute to the fragmentation and isolation of these communities, including Historical Trauma, Geographic Displacement and Isolation, Cultural and Linguistic Diversity, External Stereotypes and Perceptions, Economic Disparities, Government Policies, Limited Resources, and Lack of Infrastructure.

The National Institute on Minority Health and Health Disparities has determined that “people with disabilities often experience a wide and varying range of health conditions that lead to poorer health and shorter lifespan. In addition, discrimination, inequality, and exclusionary structural practices, programs, and policies create barriers to timely and comprehensive health care, which further results in poorer health outcomes. People with disabilities who also belong to one or more other populations with health disparities fare even worse.”<sup>2</sup> Such intersectional populations include LGBTQIA2S+ (Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual, and Two-Spirit) individuals who, because of their sexual orientation and/or gender identity, face increasing marginalization, discrimination, and targeted violence.

As the IDAC developed their approach to the Talking Circles, there were conversations on reaching other communities and breaking through existing silos. The goal was to receive the broadest possible input across

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<sup>2</sup> <https://nimhd.nih.gov/about/directors-corner/messages/health-disparities-population-designation.html>

various communities and to be able to collect reportable demographic information while also being responsive to the needs and comments of participants. The IDAC was created first to bring together different Indigenous communities across the country to identify shared challenges facing Indigenous people with disabilities. Identifying Indigenous people familiar with the needs and challenges facing those with disabilities, much less identifying those with disabilities, proved more challenging than anticipated. Too often, Indigenous people with disabilities are only considered part of the larger Indigenous community or part of the larger disability community with little consideration of the unique needs facing them because of their history, their community's sovereignty, and the different cultural views toward what others might consider a disability. The difficulty of identifying Indigenous people with disabilities who can represent their needs and those of their communities proves the need for the IDAC. Frequently, to break through the silos that exist between Indigenous communities, unless there is personal contact with a community, it is difficult to connect directly with individuals within that community. Henry sent notice of the IDAC Talking Circles to all the Native American Vocational Rehabilitation programs, which are specifically funded under the federal Rehabilitation Act 1973 to provide services to Indigenous people with disabilities living on or near Indigenous communities. There was, however, little response from these programs and no firm confirmation that the notice of the Talking Circles was provided to those served by these programs. Notice was also provided to disability advocacy organizations across the country, again with little response or confirmation that information was passed directly to Indigenous people with disabilities being served by these agencies. This lack of response from "natural" partners further demonstrates the isolation facing Indigenous people with disabilities and the need to continue building connections across communities.

Silos also exist within the disability community, such as the differences between apparent disabilities versus non-apparent disabilities, such as sensory disabilities that may be apparent as opposed to mental health conditions or intellectual/developmental disabilities that are not directly apparent. The dominant community, as well as some within the disability community, have different perceptions of the skills, talents, and abilities of individuals based on the type, extent, or origin of the person's disability. In contrast, many Indigenous communities have a distinct cultural view, diverging from the dominant community's perception of disability. Traditionally, Indigenous communities did not view a person with a disability as one who needed to be "cured" or "fixed."<sup>3</sup> Instead, regardless of disability, a person should be valued and fully included in the community.<sup>4</sup>

The IDAC initially focused on limiting the Talking Circles specifically to Indigenous people with disabilities and their family members. The number of non-Indigenous people, both with and without disabilities, who wanted to "sit in" on the Talking Circles was unexpected. The IDAC understands the interest that non-Indigenous people may have in the issues facing Indigenous people with disabilities; the Talking Circles focused on creating a safe space for people to share their experiences. This space required that those allowed to attend be limited to the intended participants and that observers be excluded. After a consensus with the IDAC group, the members

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<sup>3</sup> Understanding Disabilities in American Indian & Alaska Native Communities Toolkit Guide, National Council on Disability, February 2023, p. 9.

<sup>4</sup> *Ibid.*

agreed to create two additional sessions specifically for advocates.

It is estimated that there are almost 13.9 million (13,942,200) LGBT adults in the United States.<sup>5</sup> The IDAC modeled best practices for the collection of Sexual Orientation and Gender Identity (SOGI) data for federal statistical surveys to be inclusive of the LGBTQIA2S+ community, where people exist in yet another silo, and SOGI data was collected with the option to respond or not to respond to self-reported SOGI data.<sup>6</sup> The IDAC carefully considered what and when information was requested; however, including the LGBTQIA2S+ community proved challenging with respect to connecting with Indigenous people with disabilities, who also identify as LGBTQIA2S+. The misunderstanding of the original IDAC logo and the voluntary questionnaire demonstrated one indication of the separation between the LGBTQIA2S+ community and other communities. Initially, the IDAC created a logo that included the colors of the disability pride flag: red for physical disabilities, gold for neurodiversity, white for invisible disabilities or those that have not yet been diagnosed, blue for emotional and psychiatric disabilities, and green for sensory disabilities.<sup>7</sup>



Unfortunately, some potential listening session participants misunderstood the colors and thought they were the colors of the rainbow flag, the symbol of LGBTQIA2S+ pride, including red, blue, green, and yellow rather than gold. The misunderstanding about the colors, when combined with the questionnaire that asked participants to identify their gender and sexual orientation, led some potential participants to assume that the Talking Circles were only for people with disabilities who also identified as LGBTQIA2S+. This feedback demonstrates the typical separation between communities and the novelty of including this information in a seemingly irrelevant context. Although the IDAC focused on providing a space that was safe and respectful of all, that intent was sometimes difficult to convey. Another unexpected outcome was learning that while some needed to understand the intention of the questions, others were reluctant to provide the requested information. This reluctance is another example of the fears and real-life risks facing some individuals and communities in settings where the disclosure of self-identifying information like SOGI data, disability, and tribal identity can be viewed as dangerous to reveal.

<sup>5</sup> <https://williamsinstitute.law.ucla.edu/publications/adult-lgbt-pop-us/>

<sup>6</sup> <https://www.whitehouse.gov/wp-content/uploads/2023/01/SOGI-Best-Practices.pdf>

<sup>7</sup> History of the Disability Pride Flag <https://www.weinberg.cuimc.columbia.edu/news/history-disability-pride-flag#:~:text=The%20original%20Disability%20Pride%20flag,Magill%2C%20who%20has%20cerebral%20palsy>

# Nahat'á (Planning)

## *Developing an Indigenous Survey Approach*

### Indigenizing



Indigenization is “a process of naturalizing Indigenous knowledge systems and making them evident to transform spaces, places, and hearts.”<sup>8</sup> Margaret Kovach writes, “Methodology influences research outcomes. Research outcomes create policy. Policy generates programs. Programs guide practice.”<sup>9</sup> The IDAC team firmly believes in the importance of using Indigenous Methodologies to indigenize and decolonize in-person and online spaces in the sacred process of gathering people’s stories.

It is imperative to acknowledge and respect traditional identities while advocating for Indigenous individuals with disabilities. The IDAC intentionally followed specific protocols to ensure that the survey methodology and the care for the participants’ stories aligned with traditional knowledge practices. In Indigenous Methodologies, personal stories hold equal importance as quantitative data and are not held to the same standards as empirical data in Western academia. The IDAC report highlights the significance of the participants’ stories, and the IDAC deliberately adopted a traditional perspective to avoid the Western/colonial lens. This process included using different language and a different approach to the Talking Circles.

| <b><i>Western</i></b>        | <b><i>Indigenized</i></b>  |
|------------------------------|--|
| Listening Session            | Talking Circle   |
| Moderator                    | Circle Keeper  |
| Data                         | Knowledge, experiences, stories  |
| Presenting data/<br>research | Honoring each individual voice, each spirit who was called to participate<br>and share the story they shared with us |
| Rehabilitation               | Healing Journey  |
| Member checking              | Reciprocity and Community Input  |

Indigenous Methodologies must be rooted in Indigenous knowledge, beliefs, ethics, community, and a personal connection to oneself. Indigenous beliefs are “all about ideas developing through the formation of relationships.”<sup>10</sup> Disability itself is a constructed notion that tends to be viewed individualistically and from a deficit perspective in colonial contexts. IDAC members recognize that community relationships and culture(s) need to be at the heart of the conversation about how to understand disability from an Indigenous perspective.

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<sup>8</sup> Anon. “Indigenization, Decolonization, and Reconciliation.” Teaching and Learning Centre. Accessed January 6, 2024.

<sup>9</sup> Kovach, Margaret. “Introduction.” Essay. In *Indigenous Methodologies: Characteristics, Conversations, and Contexts*, 2nd ed., 11–12. Toronto: University of Toronto Press, 2022.

<sup>10</sup> Chilisa, Bagele, “Indigenous Research Methodologies”, 2012, Sage Publications

## Sa'ah Naaghái Bik'eh Hózhóón (SNBH)

The *Diné* framework, SNBH, guided the IDAC protocols as well as the organization of this report. The *Diné* believes all living things and creatures live in harmony and reciprocity alongside the natural world and the universe. SNBH is “expressed in concepts and values associated with natural processes identified with the four cardinal directions, including such processes as the daily cycle of day and night and the annual cycle of the season.”<sup>11</sup> The cyclical model of the four phases of SNBH teaches us to continuously reflect on and use the knowledge we have gained to create new action plans. Joy Henry, IDAC Project Coordinator, worked with SNBH as an undergraduate at Northern Arizona University. Henry led the team in using the framework, in combination with the Medicine Wheel concept of interconnectivity and harmony and the Talking Circle teachings, to guide IDAC protocols.

### Ethics (Guidelines and Protocols)

Although the IDAC members come from various traditional backgrounds, all agreed on the importance of cultural protocols. Cultural protocols are similar to ground rules, which apply to all life areas. Additionally, cultural protocols work to strengthen the overall ethical foundation of an Indigenous project; thus, the Talking Circle protocols included the person attending the virtual Talking Circles had to self-identify as an Indigenous person with a disability, a family member of a person with a disability, or an advocate working alongside Indigenous people with disabilities. The statement found in the registration included:

The IDAC is a group of representatives from American Indian/Native/ Alaskan American communities. This summer, the IDAC is holding virtual Talking Circles (“Listening Sessions”) to hear directly from Indian/Native Americans and Hawaiian/Pacific Islander Natives with disabilities across the United States. The IDAC will ask participants about the barriers they have experienced when accessing healthcare, education, housing, etc. After the sessions, the IDAC will analyze the information for common themes and make suggestions for large-scale programs or policy solutions. Any information you share will not be connected with your name or other personal identifying information. The IDAC may also use the information you provide in the future. Taking part in this discussion is voluntary. You do not have to take part if you do not want to. You do not have to answer any questions that make you uncomfortable. You may leave the group at any time for any reason.

If you CONSENT to these procedures, please continue with the following registration and enter your information. Entering your name is your e-signature for the registration, and you are consenting to IDAC to use your story.

To respect the sacred intentions of an indigenized talking session, the IDAC is limiting the Talking Circles to Indigenous people with disabilities or their family members. The 4:00 pm (MDT) listening

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<sup>11</sup> “Educational Philosophy.” Diné College, January 6, 2022 [https://www.dinecollege.edu/about\\_dc/educational-philosophy/](https://www.dinecollege.edu/about_dc/educational-philosophy/).

session of August 23rd will have a breakout room for disability advocates who want to participate.

*Agreeing indicates that you have read all of the above information, you voluntarily agree to participate, and you are at least 18 years of age (or have a guardian's permission)*

## **Community (signals relationship)**

The IDAC's goal in the virtual Talking Circles was to create a virtual ceremonial place. To achieve this goal, it was necessary for the IDAC to veer from a clinical or academic listening session; to do so, the IDAC combined cultural teachings and technology. The talking circle keepers were IDAC members who created a safe space during the Talking Circles by revealing personal connections to the three questions guiding the discussion. Doing so eased the participants and encouraged participation. The shared experiences are valuable, and the IDAC wants to give back to the community. In many Indigenous cultures, reciprocity occurs. For instance, the participants shared their lived experiences, and the IDAC gave them the opportunity to review the report before releasing it to the public. Another form of reciprocity is the IDAC, which assists the participants with their healing journey. The IDAC members viewed the Talking Circles as a ceremony since many participants came to them to reveal their needs and hurt.

## **Experiencing Self in Relationship**

Many are drawn to Indigenous methodologies because, as a whole, the approach allows for self-exploration. Indigenous belief systems uphold inward knowing arising from the self in relation to society, nature, the larger cosmos, and spirit. Like critically reflective methodologies (e.g., autoethnography), Indigenous Methodologies honor self-knowing surfacing from lived experience found in the personal story.<sup>12</sup>

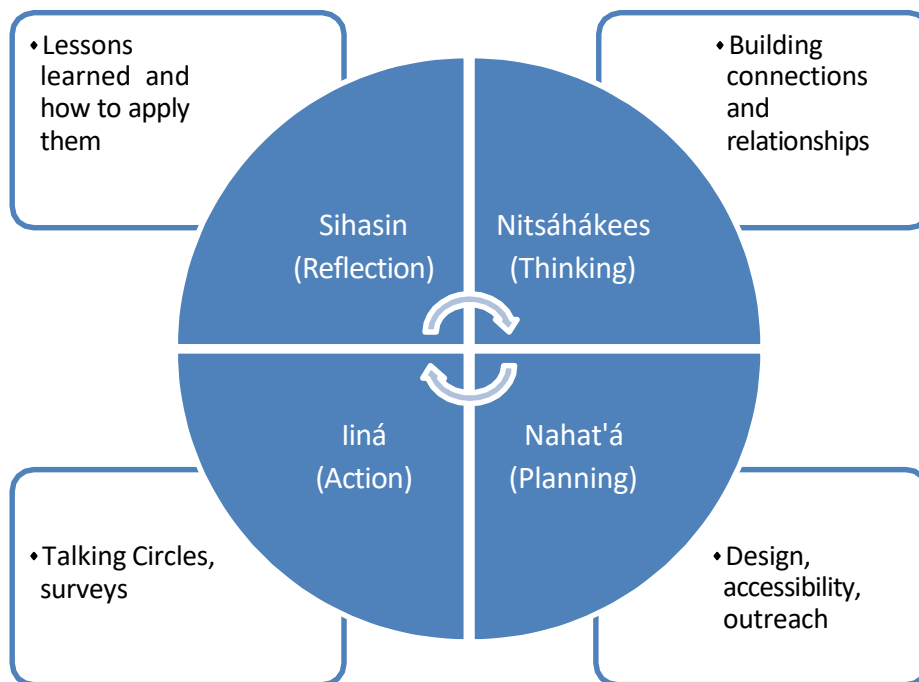
Each IDAC member has their reason for joining the IDAC. All the IDAC members have a disability or disabilities and have advocated for disability rights. Each IDAC member had unique experiences associated with their disabilities but also discovered overarching commonalities. The beauty of the IDAC Talking Circles is they nurtured both the IDAC moderators and the participants. Notably, the IDAC members felt the true nature of Benally's in-person prayer and song; his purpose and motivation aligned similarly to the IDAC members' purpose and reason.

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<sup>12</sup> Margaret Kovach, *Indigenous Methodologies* (Toronto: University of Toronto Press, 2022), 11-12.

## The IDAC Framework

The IDAC team created a framework combined the Medicine Wheel and *Sa'ah Naaghái Bik'eh Hozhoo* (SNBH). Most of the IDAC members understand the importance of the number four as there are many representations, including the four sacred mountains, the four directions, the four colors, the four worlds, the four stages of life, the four stages of the thinking process, etc. Below, the medicine wheel and SNBH were combined. This process is how the IDAC originated and is conducted. The four components of the thinking process of SNBH are heavily integrated with the IDAC's work. The thinking process begins with Nitsahakees, Nahat'a, ina, and Sihasin. Each process is a part of the medicine wheel and was integrated with almost every aspect of how the IDAC pursued its goals, including the report writing.



## liná (Action)

### *Forming and Conducting the Talking Circles*

### **The IDAC Talking Circle Procedures**



The IDAC created an intentional and proactive approach to gain a better understanding of the challenges faced by Indigenous people with disabilities. As part of their efforts, they initiated 16 virtual Talking Circles to provide individuals and families within the community with direct communication with the IDAC. Additionally, those interested in participating but uncomfortable with a group setting could arrange to provide written answers to the questions or speak with an IDAC member privately one-on-one.

The primary objective of these sessions was to identify gaps, challenges, supports, services, and barriers facing Indigenous people with disabilities. It is important to note that the IDAC places a high priority on respecting the confidentiality of all participants and, as such, has excluded any names or identifying information from the final report. However, they recognize the value of statements in participants' own words and include direct quotes in the report.

Alaina Winters writes of using Talking Circles within classrooms. Winters writes: Talking Circles, also called "peacemaking circles," come from the traditions of Indigenous people of North America, particularly tribes in the Midwest. Circle processes are based upon equality between participants and the principle of sharing power with each other instead of having power over one another. Circles are characterized by the use of a talking piece, which regulates communication. Both talking and listening are important in the circle because mutual understanding lays the groundwork for deeper, more meaningful discussions. Only participants holding the talking piece can talk. Participants who do not have the talking piece get to listen and reflect on what the person with the talking piece says. The talking piece is a meaningful and symbolic object that the facilitator, also called the "circle keeper," brings to the circle. The circle keeper often incorporates an explanation of the meaning of the talking pieces into the circle activities. Receiving the talking piece is an invitation to share with the group and helps ensure that everyone gets an opportunity to share at their own pace and in their own way without interruptions. Participants share what they want, can remain silent during their turn, or pass by giving the talking piece to the next person. The talking piece is passed clockwise around the circle, with each participant having a turn to share their authentic personal stories and have them respectfully heard and acknowledged without judgment, condemnation, nor advice (unless advice is solicited)."<sup>13</sup>

The IDAC intentionally incorporated Talking Circles into their process, drawing on the familiarity of some team members with the traditional practice. They recognized that Talking Circles are more powerful than listening sessions and provide a safe space for individuals to express their thoughts and feelings while

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<sup>13</sup> Winters, Alaina. Using Talking Circles in the Classroom. Accessed January 10, 2024. <https://www.heartland.edu/documents/idc/talkingcircleclassroom.pdf>.

actively listening to others. In the IDAC Talking Circles, the circle keepers were IDAC members skilled in understanding the importance of the tradition and connecting with participants through shared experiences and thoughtful questions. The IDAC circle keepers treated the talking circle as a genuine ceremony, showing respect and acknowledgment for each participant. This approach fostered an environment where participants displayed ceremonial protocols by respecting traditional values and beliefs. The circle keepers allowed each session to naturally unfold into a unique experience tailored to the participants without pushing for answers. The circle keepers gained valuable insight from each person's story through active listening. Overall, the IDAC team's inclusion of Talking Circles in their process was a constructive and valuable addition. The Talking Circle questions were developed based on the IDAC's goals, intended to be as accessible as possible with plain language. Notably, they were simplified and open for the participants to interpret as they answered.

## **Talking Circle Questions**

The following three questions were asked of participants during the Talking Circles.

- What challenges and barriers do you experience that hinder your overall quality of life?
- What supports and solutions have been helpful for you?
- What supports and resources do you think would help you going forward?

# Sihasin (Reflection) Talking Circle Outcomes



## Data Analysis

With participant permission, the Talking Circles were recorded and analyzed using qualitative methods. Each Talking Circle was transcribed with great care, and Deforge and Henry reviewed the transcripts, identifying the overarching themes. Using the Indigenous methodology, rather than seeking a single “accurate” meaning of data, this approach highlights the IDAC’s active role in knowledge production and honors the subjectivity the IDAC members bring to the stories participants share. As the transcripts were reviewed, Deforge and Henry focused on the meaning of the participants’ statements while also developing meaningful categories for the responses. The IDAC’s review of the transcripts and their involvement in the Talking Circles developed a creative intersection between the participants’ stories, the IDAC members’ assumptions, and the analysis of the themes. Deforge and Henry, working in tandem and alternating initial and secondary reviews while interpreting participants’ stories, prioritized the questions:

- What are participants telling us they don’t have sufficient access to?
- What is getting in the way of them accessing that area of life?

Deforge’s training as a Doctor of Occupational Therapy directly informed these questions, as she believes that the things we want and need to do in our lives are inherently linked to our culture(s).

The information provided by participants was verified using member checking, which involves participants reviewing the IDAC’s interpretations and development of themes. It also allows participants to correct technical errors or disagree with the interpretation of their lived experience, which is a form of reciprocal community input.<sup>14</sup>

### ***Question #1 – “What challenges and barriers do you experience that hinder your overall quality of life?” Participants identified barriers to meaningful inclusion.***

- Barriers to Health Care
- Barriers to Education
- Barriers to Employment / Financial Security
- Barriers to Housing
- Barriers to Utilization of Resources
- Barriers to Community Engagement
- Barriers to Independent Living
- Barriers to Legal Matters / Voting
- Barriers to Respectful Treatment
- Barriers to Leisure
- Miscellaneous Barriers<sup>15</sup>

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<sup>14</sup> Carter, R. & Lubinsky, J. (2016). Rehabilitation research: Principles and applications. (5th ed.). St. Louis, MO: Elsevier Inc.

<sup>15</sup> The IDAC adopted the framework used by occupational therapists to assess areas of strength and need.

## **Barriers to Healthcare**

Indigenous individuals with disabilities face many obstacles in accessing reliable healthcare. One of the primary challenges is transportation, which can lead to rescheduling and prolonged care delays. The input of 11 participants confirms the significant role transportation plays as a barrier to healthcare.

*“All the transportation we have is for medical but even with that if we have appointments out of town, we have to jump through some hoops to get doctor’s referrals and whatnot. Sometimes it doesn’t go through right away. [If it falls through] I call the medical facility and I usually have to reschedule.”*

– Session 9, Participant 1

*“We do have those non-emergency medical transport, but I noticed that there’s one barrier for people that are paraplegic or quadriplegic; . . . hardly any of these companies have vehicles that have a wheelchair lift.”*

– Session 9, Participant 1

Eight participants cited staffing shortages, high provider turnover, or limited access to specialized diagnosis or resource qualification as significant obstacles in Indian Health Services (IHS) and non-IHS facilities.<sup>16</sup> These impediments have led to re-traumatization, underutilization of resources, and individuals’ inability to receive necessary services due to delays or inability to obtain a diagnosis.

*“There’s such a revolving door of providers and access to them that it’s just not a well-balanced option for our community to have access to this, especially regarding mental health.”*

– Session 1, Participant 1

*“When I was younger, I would stop going [to therapy sessions] because I was tired of having to re-explain myself and re-explain my situation [to a new provider]. And so that really hindered my health, because then my mental health started going down”*

– Session 1, Participant 5

Six participants reported that healthcare providers lacked understanding of disabilities and awareness of appropriate resources, leading to misdiagnosis, poor health outcomes, and limited access to disability-related services.

*“Many IHS or Tribal or urban health care centers don’t have the state-specific training on how providers should refer, assess, etc. in a way that allows tribal patients to access the state-provided IDD services.”*

– Session 7, Participant 5

Six participants shared their input on non-culturally safe/relevant services as they experienced racism/stereotypes or a language barrier when trying to receive adequate health services.

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<sup>16</sup> The Indian Health Service, an agency within the Department of Health and Human Services, provides federal health services to American Indians and Alaska Natives. The provision of health services to members of federally recognized tribes grew out of the special government-to-government relationship between the federal government and Indian tribes. This relationship, established in

1787, is based on Article I, Section 8 of the Constitution, and has been given form and substance by numerous treaties, laws, Supreme Court decisions, and Executive Orders. See <https://www.ihs.gov/aboutihs/overview>.

*“We took [my son] to the doctor and said, ‘Hey, I think he needs to be evaluated for [early intervention]’. And the doctor went, ‘Oh no, that’s perfectly normal because you’re Navajo, so he doesn’t maintain eye contact. That’s a cultural thing.’ It’s like, Yeah, but he’s at home with family. We maintain eye contact when we look at each other because we’re familiar with each other. And as a parent, I know this is not right.”- Session 6, Participant 1*

Five participants mentioned the Indian Health Services (IHS) specifically and the limitations associated with IHS, such as having only IHS insurance, which limits one’s access to care, leads to long wait times, involves complicated paperwork, and lacks funding limits services.

*“Over the years, I have had to file many complaints...these various issues with IHS...sometimes they were followed up...the appropriate responses were given of, ‘I’m so sorry that happened to you.’ [... but the question is], ‘What are you going to do about it, so it doesn’t happen again in the future or to someone else?’”*

*– Session 4, Participant 2*

*“Accessible health care [is a barrier]. I mean, we do have IHS, but the lines can be long, the waits can be really long, and a lot of times they’re not covered like if you don’t have your paperwork to apply for Indian Health Care, then you know, you’re not really able to get access to healthcare in some places.”*

*– Session 7, Participant 3*

*“I’ve been trying to work with local IHS myself because I’m a blind individual and I have been trying to ask them to accommodate blind individuals with our pharmacy, medication. All I get is funding, they bring up funding a lot and I told them well, there’s laws that protect us, and we should have accommodation.”*

*– Session 9, Participant 1*

Three participants mentioned disability-based income restrictions and difficulty affording basic healthcare.

*“I have a doctorate degree but I’m not paid like I have a doctorate degree. [...] I have to either turn down work so I can be on [the state’s] health insurance. Or I have to work so much that I get myself sick, and sicker. [...] But I am an intelligent person who wants to work and provide for my family. [...] disability so often forces us into poverty, where we now have even fewer choices than we had before.”*

*– Session 2, Participant 3*

*“With disabilities, it is always harder to find that knowledge or whatever that can treat us accordingly or knows our history or our disability and what has happened. I think it all goes back to being confident in disability knowledge and willing to learn if they don’t know.”*

*– Session 4, Participant 1*



## **Barriers to Education**

During the discussions, five participants described instances of stereotypes, discrimination, or stigma within the education system, either personally or in relation to their children's schooling.

*"[public schools] believe that you being Native, you're already behind the bar of a student who is non-Native."*

– Session 1, Participant 1

*"Some of [the parents of students with disabilities] are reluctant because they don't want their child to be identified that they're in special education."*

– Session 6, Participant 3

Seven participants mentioned a lack of caregiver knowledge or confidence to advocate for their student's rights.

*"You have a lot of grandparents that are taking care of their grandchildren. And I feel like in these IEP meetings they're using a lot of language and words that they don't really understand and they're not really understanding what their rights are. [...] I just like my community, to know what resources are available for them. I don't want them to feel like all is lost or they're helpless and they have to go do the things that I've had to go through with my son."*

– Session 3, Participant 1

Four participants highlighted the need for culturally relevant education or accommodations for Indigenous students.

*"Aside from [academic] accommodations, there also needs to be discussions with their counselors about like, time spent attending ceremony. And sometimes even that's, like, met with reluctance."*

– Session 7, Participant 8

Four participants mentioned their financial burdens regarding education.

*"You oftentimes have to choose between education or employment to help your family."*

– Session 1, Participant 1

*"I was unsure of my ability to secure a career in which I got paid enough. There seems to be this hump or this gap, where state funding, federal funding, help for people with disabilities ends. And there's this great desert in between that support ending and me having the resources myself to live a dignified life."*

– Session 2, Participant 1

Fourteen participants go into detail about physical and logistical accessibility of necessary supports (e.g., lack of automatic doors, accessible transportation, and virtual options; professors denying legally mandated accommodations; schools not lawfully providing mandated services and therapies).

*"...Our mobile doors or automatic doors aren't working, so a lot of our students that are in wheelchairs aren't able to get into the disability department, which is really problematic."*

– Session 7, Participant 8

*"[They tried to remove my son from the special education program] because they didn't have a speech therapist at the school that he was going to attend."*

*– Session 7, Participant 9*

*"Even at [IEP meetings], we still struggle. We've had to take the school district to court"*

*– Session 3, Participant 1*

### **Barriers to Employment / Financial Security**

Five participants revealed their employers' lack of understanding of appropriate accommodations or willingness to offer them.

*"There's definitely a great divide between words and actions in terms of employment, accessibility, opportunities. [...] it's about employers' lack of knowledge about disabilities. Information sharing needs to be done with employers, before they will actually understand that people with disabilities are totally capable of doing the jobs, you know, with the right accommodations."*

*– Session 4, Participant 1*

*"[...] needs to be some sort of like cultural competency training or cultural sensitivity training because it's like, it's not a vacation [...] maybe understanding that there are people that need that just for their wellbeing and mental health and you know, for everything, right? Like all aspects of life, like oftentimes ceremony is a huge component in our lives. And I think that's something that really needs to be addressed [...] I'm finding other people still sharing the same experience of, like, their job not accommodating that time off for them to attend ceremony and for them to pray."*

*– Session 7, Participant 8*

Four participants mentioned physical and mental challenges of obtaining and maintaining employment.

*"I spent good chunks of time not being able to work for physical reasons or mental health reasons."*

*– Session 2, Participant 2*

*"Sometimes you have to put in extra preparation to be considered, you know, even to be given just an opportunity to apply for a job. [...] and then once they gain employment, then there's the issue of keeping employment. The ongoing need for support in that area."*

*– Session 4, Participant 2*

Four participants mentioned difficulty navigating the process of receiving Social Security disability benefits.

*"I don't want to deal with getting denied and going through all the paperwork and being out of work and poor as hell for a year and a half to two and a half years before you finally maybe get accepted to get on disability. [...] So I just work. And as a result, I have been in autistic burnout for 10 years."*

*– Session 2, Participant 2*

*"And then some will have medical diagnoses but then they're [still] not eligible for Social Security benefits."*

*– Session 6, Participant 2*

*"The hoops you must jump through to get [SSDI, etc] and keep those programs are a lot."*

*– Session 2, Participant 4*

Three participants mentioned that the extra time it takes them to navigate systems results in limited

opportunities to engage in other meaningful occupations.

*“Oftentimes you have to, you know, sacrifice other areas such as employment or, you know, even leisure time just to try to navigate the system.”*  
– Session 5, Participant 3

Three participants mentioned government income limitations for people with disabilities, resulting in a lack of agency and negative impacts on health.

*“I don’t have the resources, partially because the government won’t let me provide for myself to try to buy my way out of ableism and whatnot. So how am I supposed to live, you know?”*  
– Session 2, Participant 4

Two participants mentioned discrimination or fear of discrimination based on their Native and/or Disabled identity.

*“I was thinking of applying for, like, a job anywhere. And it feels like you’re competing with other people that are sighted. And then you just get this question that people ask you, ‘are you sure you can do the job?’ And [...] I’m afraid if I do apply, I’m gonna get rejected or denied.”*  
– Session 9, Participant 3

## **Barriers to Housing**

Six participants mentioned a lack of affordable and accessible housing for all ages.

*“Affordable housing is rare, accessible housing even more scarce and Natives who are not residing on tribal land do not have the same assistance from HUD as those living on reservations.”*  
– Session 7, Participant 7

*“There’s no accessible housing for people that are younger than 55, as well here on the reservation.”*  
– Session 9, Participant 1

Six participants mentioned insufficient funding and perceived lack of support from their tribe.

*“I would tell [my tribe], you can keep my revenue check if you could help me this month, you know, it’s coming in three months, but I need financial support now for something or housing. I would get denied.”*  
– Session 1, Participant 1

*“Living off the reservation, we don’t qualify for a lot of different services. [...] I’m working every day trying to make sure that we pay the rent and pay our bills”*  
– Session 6, Participant 1

*“[If you live on the reservation] there’s not a lot of [housing] options available, there’s not a lot of funding. And then, if you do have the funding, you have to have the land. And that’s not always the option for a lot of tribal communities.”*  
– Session 1, Participant 1

Three participants mentioned logistical/bureaucratic hurdles and poor cooperation/communication between programs within and between tribal, state, and federal levels.

*“Even when you have all the programs in place, they still don’t work [...] There are all these different programs to help someone like me buy a home, but none of them work together.”*

*– Session 2, Participant 4*

Three participants mentioned months-to-years-long waits for housing assistance or home modifications.

*“I applied for housing assistance. And it took like almost a year.”*

*– Session 5, Participant 1*

*“A person did come out, did the assessment and everything, took photos and said they’ll get in contact with me, most likely I’ll get a ramp built. But I haven’t heard anything about that again. And it’s been over a year now.” -Session 9, Participant 1*

One participant mentioned a lack of space due to multigenerational living arrangements.

*“I work on the reservation. A lot of our families live in multifamily housing. So sometimes if a child needs feeding equipment, or if they have an oxygen machine, you know, we always look [if there’s enough physical space] that’s always my concern.”*

*– Session 6, Participant 2*

### **Barriers to Utilization of Resources**



Six participants mentioned a lack of knowledge of available resources that could have assisted them in transitioning when they became disabled or resources that could have supported their efforts toward independence.

*“Growing up on the reservation, I didn’t know you guys were around [Native American Disability Law Center], I could have used you in high school. I could use you in college, I could’ve used you in law school.”*

*– Session 2, Participant 1*

*“Parents and the students, they need to be aware of what kind of assistance, what type of accessibility, is available to them.”*

*– Session 6, Participant 3*



*“I acquired my disability when I was 17, I was diagnosed. And it was hard for me because I didn’t know what services to look for, what services I may be eligible to receive.”*

*– Session 5, Participant 1*

Three participants mentioned a lack of trust in the systems and professionals related to historical trauma.

*“Within my community, when we provide resources, or other organizations or something, you know, they’re very hesitant, because there’s all that historical trauma, there’s everything that goes in connection, [...] you don’t know exactly what to expect, what services they can provide, or who you can talk to.”- Session 1, Participant 1*

Three participants mentioned a lack of funding for culturally safe and responsive programming or services, and the stereotypes and stigma associated with services.

*“It hinders me from telling people ‘oh hey there’s this resource’ or ‘hey, you can try this’, because I’m worried that they’re gonna get the same feedback that I got [that the only way to solve my problems was to leave the reservation]”  
– Session 1, Participant 1*

*“Sometimes it seems like in order to receive services or proper care that you’re entitled to [...] you have to leave the reservation, which is your home, it’s where your intermediate family and your whole support group is at and I just think that in a lot of ways, some of the programs that are set up, have a focus on that individual self-view, whereas us Native Americans tend to have a more collective outlook, where we think of the whole group as a whole.”  
– Session 5, Participant 3*

Four participants mentioned a lack of physical or logistical accessibility, including inconvenient locations, lack of transportation, lengthy paperwork, disconnect between tribal and local social services, and time filled by other occupations. The lack of coordination among federal, state, tribal and private resources create significant barriers.

*“Individuals with the disability often have to navigate a system that is extremely difficult and bureaucratic to navigate. As was mentioned, with the processes and, the paperwork, and the working with different agencies, it can be very difficult to navigate the system as well as your life. So you know, attending medical appointments and everything like that plus keeping employment.”  
– Session 5, Participant 3*

Two participants mentioned difficulties accessing technology.

*“I can navigate accessing Zoom and whatnot. But there’s other people who [...] are having a hard time doing that because there are a number like I said, nobody here to help them, teach them.”  
– Session 5, Participant 2*

### **Barriers to Community Engagement**

Three participants mentioned a lack of accessibility to community buildings and events and a lack of accessibility to health care, educational, employment, and housing facilities.

*“[Our tribe] didn’t really include him in [the youth programming]. Or think about people like him, you know, wanting to participate in things that our community has going on. [...] I want him to be a functional member of our society. And in doing that he needs to learn how to, you know, really be a part of our community. And I feel like he’s been excluded.”  
– Session 3, Participant 1*

*"[My tribal government doesn't seem to] abide by the ADA. Then at the chapter [houses...] I really haven't been to a meeting but a lot of times they don't have accommodation for blind people as well."*

*– Session 5, Participant 2*

Two participants mentioned transportation and travel logistics. One participant cited long hours at school as restrictive to her son participating in tribal programs that might be beneficial to his mental health and sense of community support/belonging.

*"We do have transportation problems and we do need transportation on the reservation. I, for one, experienced the same things, like going to the store and going to different places I need to go like the chapter house I need to go sometimes but transportations is lacking"*

*– Session 9, Participant 2*

*"But I don't see [a lot of tribal programming] with our children. And I know that some of it is that our kids go to school, and like I said, they go an hour away. So, my son gets on a bus at seven in the morning, and I don't see him until about five in the afternoon. [...] They're out of their environment when they leave our reservation every day, and they just want to feel supported."*

*– Session 3, Participant 1*

Four participants mentioned discrimination or stigma related to Indigenous, disabled, and/or queer identities.

*"I guess they're so used to saying, 'Don't say that. Don't be talking like that.' But for me, I like to educate the younger generation, as they do ask questions sometimes when they see me out in public. I hear [their elders say], 'You don't need to know that' and stuff like that. I just tell them. 'That's okay. It's nice that young kids are curious. It makes it easier for them to understand what these are for. They're not toys, or they're our blind person's tool for us to use.'"*

*– Session 9, Participant 1*

*"Sometimes [in Native communities], having children that have disabilities are almost seen as being taboo. And [parents are] almost kind of like, sometimes in denial. And, you know, don't want to admit that maybe there is a problem. And that's really hard to break that barrier with my own people."*

*– Session 3, Participant 1*

*"My tribe is pretty anti-queer. And they're pretty ableist"*

*– Session 2, Participant 4*

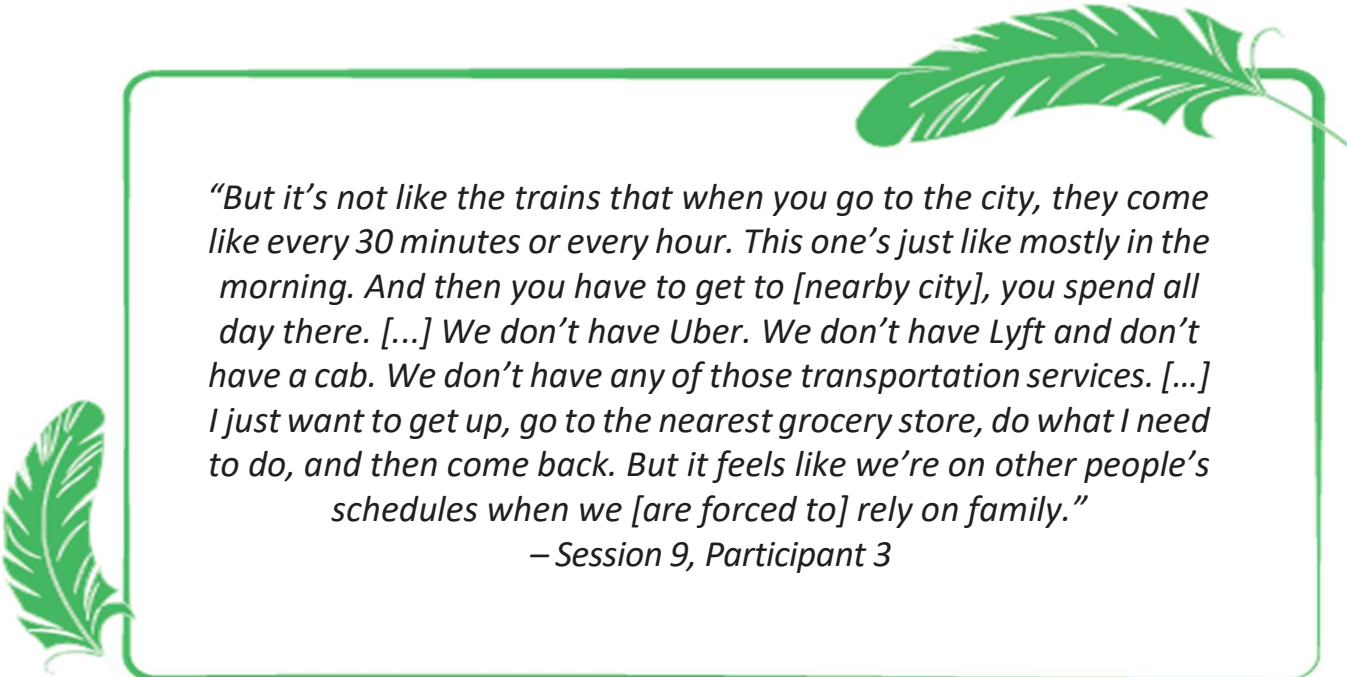
*"[The Indigenous community] seems a lot more closed off, and I've had a harder time getting into community. And there's not really a cohesive Two Spirit community here, either. If you were, if you were full blood native, you didn't want anything to do with us. And if you were white, you didn't want anything to do with us. So, we had our own Mixed Blood community that we created for ourselves."*

*– Session 2, Participant 2*

One participant mentioned that chronic pain and autoimmune disorders keep them confined to bed most of the time, unable to participate in community events.

## ***Barriers to Independent Living***

Four participants mentioned a lack of reliable, flexible, and timely transportation. Transportation options are not always safe or accessible, and the time spent on inefficient transportation restricts the time they have available for other areas of life.



*“But it’s not like the trains that when you go to the city, they come like every 30 minutes or every hour. This one’s just like mostly in the morning. And then you have to get to [nearby city], you spend all day there. [...] We don’t have Uber. We don’t have Lyft and don’t have a cab. We don’t have any of those transportation services. [...] I just want to get up, go to the nearest grocery store, do what I need to do, and then come back. But it feels like we’re on other people’s schedules when we [are forced to] rely on family.”*

*– Session 9, Participant 3*

*“[There is] no public transportation whatsoever to go to the grocery store, or even go to the nearest border town to do some shopping.”*

*– Session 9, Participant 1*

*“Sometimes the rides... it should be a 15-minute ride, but it’s like a two-hour ride.”*

*– Session 9, Participant 4*

One participant shared that they cannot physically access their apartment’s laundry room independently. Another shared that their ability to care for their grandson depends on maintaining good health, which has been challenging. Another expressed frustration that they were spending so much money paying a home health aide that they often couldn’t afford to eat.

## ***Barriers to Legal Matters / Voting***

In addition to difficulties with the physical accessibility of polling sites and limited availability of mail-in voting, participants mentioned a variety of complex legal barriers. For example, one participant is facing discrimination and bureaucratic hurdles in changing from an English name to an Indigenous name. They have been told that their name is too long to be on a driver's license, so their ID card does not match their insurance card, resulting in canceled appointments (i.e., delays in necessary health care).

*“And I’m having the biggest battle between my health insurance company in VA Department of Motor Vehicles of getting my ID corrected with the correct spelling of my name, because my name is long. They’re claiming it can’t be enough characters. But I’ve seen people that...whose names are longer than mine on an ID or driver’s license.” -Session 8, Participant 1*

Another participant shared their observation that there was “a lot of overlap in families that were involved in child welfare with intellectual and developmental disabilities who weren’t always accessing the services that either the children or parents involved in those cases needed” (Session 7, Participant 5). Up to years-long delays with completing lengthy paperwork (due to inadequate support or accommodations related to the client’s intellectual disability) can appear to the court as non-compliance, which delays or prevents parents from getting their kids returned to their care.

When talking about advocating at the tribal government level for disability-related protections and services, one participant commented, “If you don’t have the right last name, or if you’re not, you know, around where you can bug them in person, then it doesn’t seem like your issues really matter anymore” (Session 2, Participant 1).

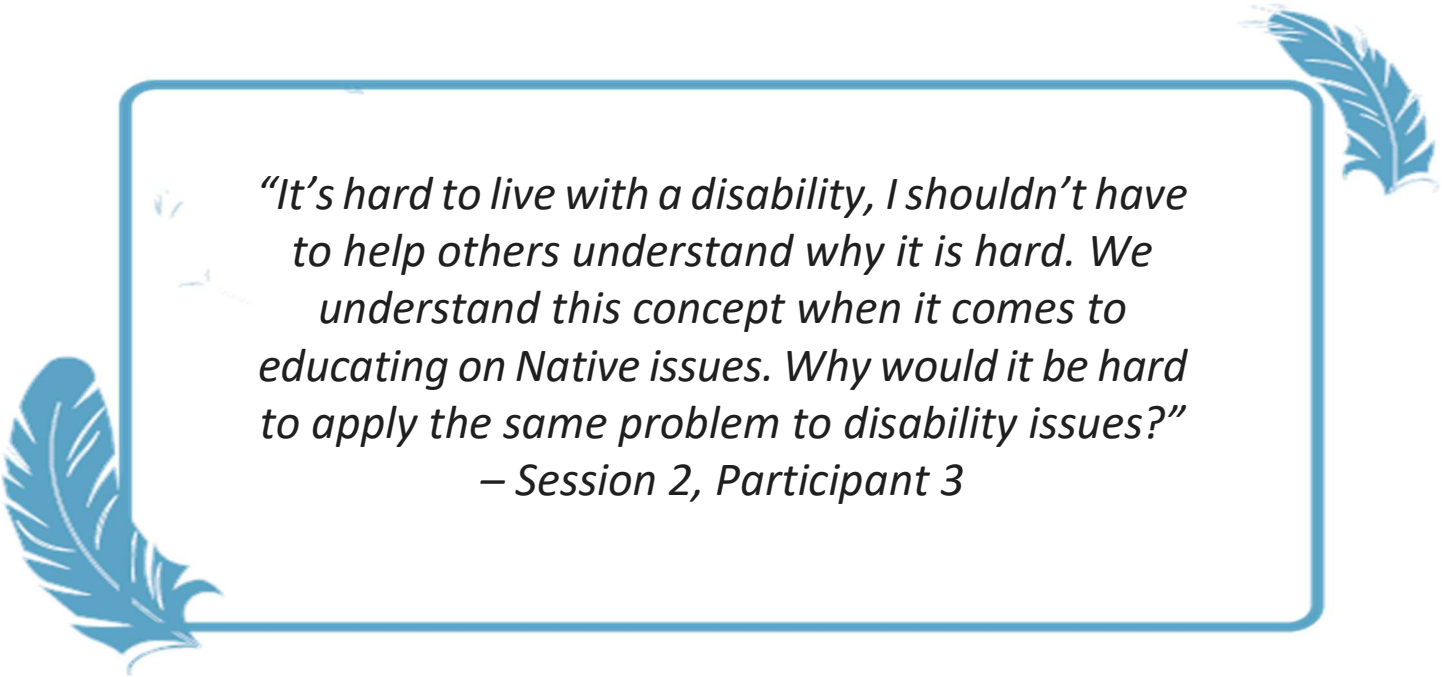
Another participant similarly commented that disability-related services and funding do not appear to be priorities to their tribal government, citing a lack of transparency about how much funding is allocated in the areas of disability and special education.

## ***Barriers to Respectful Treatment***

Stigma, stereotypes, racism, ableism, and gender bias negatively impacted participants’ self-esteem and self-concept. Participants cited society’s general ignorance and misunderstanding of Indigenous historical context as well as a lack of appreciation for our resilience.

*“What they’re not seeing is, you know, the strength of the people that live in those [seemingly unkempt] houses, and what they’ve overcome...deal with on a daily basis. I’m consistently being treated like I am not capable of, you know, much. It gets a little frustrating after a while.”*  
– Session 4, Participant 2

Another participant lamented what they perceived as their own community’s blind spot – a lack of empathy for the struggles disabled people experience.



*“It’s hard to live with a disability, I shouldn’t have to help others understand why it is hard. We understand this concept when it comes to educating on Native issues. Why would it be hard to apply the same problem to disability issues?”*

*– Session 2, Participant 3*

### **Barriers to Leisure**

One participant experienced autistic burnout from working just to afford basic living expenses, which has resulted in no energy for participation in other meaningful life activities. For another, their limited time for leisure pursuits is related to time and effort spent navigating the healthcare system. A parent advocating for their child during the Talking Circle commented:

*“We live in such a rural area, that there really isn’t too many things that accommodate him, like I see in bigger cities, such thing as having a sensory time at the recreation.”*

*– Session 3, Participant 1.*

### **Miscellaneous Barriers**

One participant bravely shared their story of how their disability and government-imposed restrictions on income effectively trapped them in a situation of domestic violence during the COVID-19 pandemic.

*“Because of being chronically ill and housing costs, it forced me to live with a partner that I shouldn’t have been living with [during the pandemic]. And I wanted to leave that relationship but couldn’t because of money. The choice becomes stay in a violent situation for you or be houseless” [...] “if I can’t make more than \$1,500 a month, of course, I’m going to be put in scary situations like a lot of other women [...] that’s one of the core issues is having economic agency. And disability so often forces us into poverty, where we now have even fewer choices than we had before.”*

*– Session 2, Participant 3*

Two participants mentioned the extra labor required of them, commenting that disabled people are expected to create solutions to our barriers and then educate others. They also said that having intersecting identities means knowing everything about Native rights and disability rights and services.

*“The onus of all the work gets put on us so much to not only find the resources and survive, but then to educate other people.”*

*– Session 2, Participant 3*

*“You have to know about your Native rights, your treaty rights to argue about every damn thing, like when it comes to hunting, fishing, gathering, my education, but also now I got to be, you know, a specialist in my medical care, Medi-Cal, Medicare, any work-related HMOs, HSAs, HRAs, and know those down to a tee be- cause we’ve got to fight for them tooth and nail, every single session that we do every single doctor’s visit or therapy or durable medical equipment. I have to be a specialist on wheelchairs. I’m not, you know, Native enough for Natives, I’m not disabled enough for the disabled, and it’s exhausting.” -Session 2, Participant 1*

Also related to intersectionality, two participants noted the lack of disability advocacy groups that specifically address Indigenous peoples’ needs and the importance of continuing the IDAC’s advocacy efforts beyond the time frame of the initial grant.

### **Question #2 - “What supports and solutions have been helpful for you?”**

In total, participants identified ten forms of support.

- Advocacy, Peer Support
- Indigenous Culture
- Healthcare
- Transportation
- General Accessibility
- Utilization of Resources
- Employment/Financial Security
- Education
- Housing
- Voting/Legal

Many participants find that advocacy and peer support are essential pillars of their support system, with eight citing these resources as particularly helpful during challenging times. For instance, in 2020, a coalition of 16 members comprised of individuals from the Navajo Nation and Hopi tribe came together for mutual support and community advocacy. Known as the Northern Arizona Tribal Disability Coalition, the group meets monthly to address disability concerns and promote advocacy. Notably, the group has established connections with other advocacy organizations, such as the National Federation of the Blind, demonstrating the effectiveness of networking in learning about and joining advocacy efforts. Grassroots teachings influenced many of the support systems and groups mentioned by participants.

Cultural identity was another source of support that proved beneficial to the participants. Specifically, the participants drew strength from their connection to their Indigenous teachings, with ten individuals highlighting their culture’s role in helping them overcome hardship and obstacles. In some cases, Western healthcare practices were integrated with traditional Indigenous ceremonial activities to provide comprehensive support. As one participant noted, these cultural connections proved invaluable during difficult times.

*“We come from generations of strength. I remind my sons about this, probably more often than they would like me to, but just knowing your bloodline, what the accomplishments of your ancestors were, and reminding yourself about those during the troubling times, the dark times, because there are plenty, there have been plenty of those times. And knowing that you’re not alone, you’re never alone. Even when it feels like you’re alone, you’re not alone. Also, I think the power of ceremonies, the power of prayer, and cultural practices, those things are sustaining, and those practices are the reason why we’re still here today, given all of the attempts to eliminate us, and it hasn’t succeeded. And so, it’s very empowering when you think about your tribal people. [...] I’ve lived in different tribal communities, and it’s just so*

*inspiring and astonishing to me, the strength in each one of those communities. [...] the internal aspects that help people with disabilities be successful, our culture, your cultural practices, and teachings, you know, implementing, you know, staying close to those keeping them, you know, a part of your daily life, because that is hard to, because most of the time, we're interacting with, you know, the non-native world. And it's easy to, you know, forget some of the things that you've been taught, or, you know, forget to, you know, pray every day in the way that you were taught. And it's, but it's so important."*

*-Session 4, Participant 2*

Nine participants commented about healthcare. Many shared their experiences of receiving healthcare assistance, and one participant expressed the support they have received.

*"I have a caseworker. I have received medical referral services from Native American Lifelines. [...] And my caseworker tries to help me with as much as they can, like if I need help with paperwork or different things, and they provide like medical transportation for certain instances to and from the office."*

*- Session 8, Participant*

Eight participants shared how they utilized resources or connections that assisted them, and one participant discussed how networking helped them reach resources.

*"Utilizing the power of networking...me talking to other people knowing...friends or family or people I meet even strangers sometimes...knowing people that know the things I need to know that I don't know yet."*

*- Session 4, Participant 2*

Six individuals shared their experiences of transportation resources and assistance. One participant shared their community health resource center assists with transporting tribal members to nearby cities for appointments. An IDAC member shared a resource that was made by the community. The resource is a Facebook group devoted to assisting individuals with rides between Flagstaff and Phoenix health care and medical services.

*"I've been seeing a lot of people utilizing ["catch-a-ride"] Facebook groups] for just going to like Flagstaff or Phoenix for health care and medical services."*

*- Session 1, IDAC member*

During the session, six participants shared their personal stories about employment and/or financial security. Some of the participants mentioned a few programs that helped them locate suitable jobs.

*"Programs like Voc Rehab, have a service model that provides that level of support to help a person gain a job, and then keep it."*

*- Session 4, Participant 2*

Another example of a participant using a well-known assistance, and specifically this participant used it to get assistance with securing a job.

*ASSIST! To Independence, the independent living center, "they helped me, they got me a support they actually got me a typical kind of small job that I was actually doing at that time and support they gave me so much support that I could literally believe that okay, I'm now capable of doing most of the things I used to." -Session 4, Participant 3*

Five participants mentioned resources that have helped them with voting or legal services issues. The resources mentioned by the participants are mail-in and absentee ballots, hybrid technology, and the

Native American Disability Law Center.

*“[Advocate] to every county that has a tribal community, or tribal nation within it to allow for absentee voting on one day. For no justification, you don’t have to have any medical [reason] or anything.”*  
– Session 2, Participant 1

Four individuals shared their educational experiences, with some currently attending college away from home. They noted that their college campuses have valuable resources, such as support groups and disability departments. Furthermore, one person spoke passionately about the importance of having an Indigenous representative on the special education advisory panel, explicitly mentioning that their state has 22 federally recognized tribes and, therefore, needs Indigenous representation.

*“I was very impressed that they actually, you know, designated one of their, one of the positions on their seat panel to be for a native representative.”*  
– Session 4, Participant 2



Three individuals have shared their accounts of receiving aid for housing or programs that enabled them to make their homes more accessible. For example, a wheelchair user recounted how a collective effort by a group within their community helped them and others on the reservation to improve their home’s accessibility.

*“With the Navajo Nation, there’s the independent living, you know, they go out and [improve] accessibility in the homes.”*  
– Session 6, Participant 2

Lastly, three individuals discuss general accessibility. One wheelchair user shared how a video system obtained via grant allowed court proceedings to be hybrid and how the hybrid model allowed the person to access law school.

*“I wouldn’t have been able to go to law school without those without the hybrid program.”*  
– Session 2, Participant 1

Another participant shares a group that has assisted them in making their home more accessible.



*“We do have one of the Centers for Independent Living, called ASSIST! To Independence. I did reach out to them, well they did reach out to me about the ramp and asked if I needed a ramp. I said yes. So, they did a referral and sent it to the Navajo Nation. I believe it’s called OSERS [Office of Special Education and Rehabilitation Services]. And that’s where this lady came from to me, and she took photos and everything, and she said they usually help people that need ramps.”* – Session 9, Participant 1

### **Question #3 - “What supports and resources do you think would help moving forward?”**

The participants discussed 15 areas of suggested improvement in the Talking Circles.

1. The Indian Health Services (IHS)
2. General Accessibility Recommendations
3. Indigenous Visibility and Knowledge
4. Healthcare (non-IHS)
5. Virtual Accessibility
6. Transportation
7. Employment/Financial Security
8. Information Sharing
9. Education
10. Advocacy, Peer Support
11. Link Tribes and Surrounding Communities
12. Legal
13. Tribal Responsibilities/Requests
14. Internal Factors
15. Housing

Eight individuals provided valuable feedback on the Indian Health Services (IHS). One participant suggested that Indigenous people should receive the full total allocation of IHS funding, particularly those living off-reservation. Another participant recommended that IHS health providers receive cultural and disability training to better serve their patients. Additionally, there was a strong call for IHS facilities to establish disability advisory councils. Two accessibility requests were also made, including the installation of self-serving kiosks and braille or QR codes on prescription bottles. Another crucial area of focus was the need to train IHS medical providers in diagnosing disabilities and implementing policies to accommodate people with disabilities. Finally, it was suggested that Section 504 be enforced to address discrimination against Indigenous people with disabilities within the IHS.

*“[...] make their kiosks blind people friendly, where it has a voiceover on there. For us, as blind individuals, to go in and utilize that machine ourselves rather than asking somebody else or having somebody go with us.” – Session 5, Participant 1*

*“I feel like a lot could be done in terms of training IHS staff about how to effectively listen to their patients with disabilities. There’s been incidents of racism because of the non-native medical providers, and their stereotypes or whatever beliefs they might have had. Over the years, I have had to file many complaints about these various issues with IHS and sometimes they were completely ignored. And sometimes they were followed up on and the appropriate responses were given of, “Oh I’m so sorry that happened to you.” And I think that’s why I learned through that whole process, is the next important question is for me to ask them, “What are you going to do about it, so it doesn’t happen again, in the future or to someone else?”*  
– Session 4, Participant 2

During the Talking Circles, two individuals made general accessibility recommendations. One requested a digital format for medical documents and described in detail how some blind individuals utilize voiceover functionalities to read to them independently. The other participant wished to include all family members in conversations about supporting children with disabilities.

*Family's also very key, they want to be involved. So, you're not only educating, but you're also getting them included, and you're talking to them about what services are available. What does the disability mean to your child, what does that entail, so they're aware of it and they can have a say and continue to pull them back in and let them know that, you know, everybody in the home is important and why they're and to center around and providing that support to them only to their own family members."*

*– Session 6, Participant 3*

Insights on Indigenous visibility and knowledge were gathered from eleven individuals, with a focus on the need to normalize the presence of Indigenous people. This can combat the fetishization of their culture and eliminate the perception of them as a “past group,” as well as address forms of oppression towards Indigenous people. Participants expressed a desire to integrate traditional knowledge with Western healthcare services, emphasizing the importance of educating medical providers on traditional healing and medicine. To facilitate this, cultural safety training was suggested for healthcare providers, college administrators, and employers.

Other ideas discussed included reimbursing traditional healing practices and providing culturally appropriate services. Participants also stressed the significance of educating policymakers on reconciliation, decolonization, and indigenization, requiring Indigenous individuals to share their historical trauma and personal stories. One participant envisioned the evolution of the IDAC into an organization that advocates for tribal government change. Additionally, creating tribal scholarships specifically for healthcare-based education could increase the number of Indigenous employers in healthcare. Finally, a trauma-informed, culturally safe space created for Indigenous veterans was proposed.

*“More opportunities, like the space today for advocates, service providers, and other representatives to meet and share information.”*

*– Session 8, Participant 1*

One participant mentioned that they strongly preferred keeping hybrid options available for all known resources accessible to the public. They explained that during the initial phase of the COVID-19 pandemic, hybrid options had become a viable and highly effective alternative to in-person events and meetings. Another participant chimed in and shared how much they appreciated the hybrid options as it had made it much easier for them to attend important events they would have otherwise missed.

*“I advocated that for myself, not only as a wheelchair user, but all the elders in the community who just can't get out to the courts for their grandbabies, or their family members, or all the people who live off the reservation who are trying to, you know better their lives, they don't have time, nor the resources to go back to the reservation for things that they need to be there for [keeping virtual options or at least hybrid options].”*

*– Sessions 2, Participant 1*

During a discussion on transportation, three individuals offered their perspectives. One participant expressed a desire for an affordable and easily accessible mode of transportation between their home and school, citing the limitations of living on a reservation. The other two participants emphasized the importance of their community having access to reliable and convenient public transportation, identifying the current lack thereof as a significant issue in need of attention.

*“And just having those resources it's going back to having the resources and the access, where our reservations are, you're very minimal to get access outside of the reservations if you're fortunate to have that opportunity to have your own transportation to have support from your tribe that can take you to a specific area as if you want to continue your education after high school.”*

*– Session 1, Participant 1*

During the sessions, seven participants shared their valuable insights on employment and financial security. A particular request was made for financial assistance to support parents in caring for children with disabilities. Three individuals raised concerns about the need for advocacy to help Indigenous communities learn financial literacy and secure employment. Another participant suggested educating employers on how to engage with individuals with disabilities in the workforce. The groups also emphasized the importance of inclusive practices and dignified, accessible job opportunities for people with disabilities.

*“I think the community and government, I think they should try to focus more attention, I think more effort into us...I think there are some things disabled people can do actual normal people cannot do...the kind of job that you need to be sitting down doing them for a long time...I think some of the disabled people wouldn't mind sitting down at a very long time doing most of those jobs.”*

*– Session 4, Participant 3*

*“To educate all companies and employers of how to be inclusive because I think they just say, “Oh yeah, we are inclusive!” But when we get to the oppressed questions, it turns out they're not really inclusive or willing to change their practices. We need to go to them and correct those so we have an equal workforce.”*



*– Session 4, Participant 1*

In regard to sharing information, a participant proposed utilizing various media platforms to broaden the reach of disability resources. Another recommended creating an online resource page that can be accessed by all communities and shared with individuals with limited access to technology. Lastly, a participant expressed interest in receiving information on services specific to the Indigenous community.

*“So, media is something that's important that you disseminate the information to a larger group.”*

*– Session 6, Participant 3*

According to the feedback received from 10 individuals, it is crucial to address the challenges faced in the education sector. One of the suggestions put forward was that increased funding can help improve the education of Indigenous youth. It is also important to identify and provide beneficial educational opportunities to enhance student learning. Punishing truancy is not the solution, instead, research and support can address the root cause of this issue more efficiently. In addition, it is essential to teach stress-coping skills in schools, and parents must be educated on their rights to advocate for their children with disabilities. Encouraging open communication and compromise between schools, families, and tribes can also help improve the education system. Habitat for Humanity can assist in this regard by building accessible and livable houses for educators on the reservation. Having Indigenous representatives on state special education advisory panels can also be helpful in addressing the needs of Indigenous children with disabilities. Finally, training college employees to work with students with disabilities and educating parents on available resources and benefits of diagnosis and school-based services can further enhance the education system.



*“If I can get more advocates in my area to let parents know what their rights are then maybe they’ll have the confidence to advocate for their children in the way their children needs to be advocated for.”*

*– Session 3, Participant 1*

*“Teaching them [parents] about the resources that are available. There’s assistive devices, there’s Independent Living, there’s Vocational Rehabilitation, there’s post-secondary education now in post-secondary education, they have, you know, a disability center and the universities that they can, you know, work with, when there are any challenges that their child is facing. So, I think their involvement, providing them the resources that they need, why the role as a parent, or as a guardian is very key.”*

*– Session 6, Participant 1*

During the meeting, several participants provided valuable suggestions on advocacy and peer support. It was heartening to note that 15 participants emphasized the importance of uplifting voices. One participant proposed creating a shared network system in-person, virtually, or hybrid for moral support and advice. Another participant suggested that both state and tribal agencies should advocate for disabled individuals, taking into consideration the intersection of Indigenous and disability cultures. Reframing the Western perspective of how to approach disabilities, neurodivergence, etc., in tribal communities was suggested to promote resilience and reduce stigma. There was a consensus that Indigenous youth and young adults should be educated on advocacy as they often need to advocate for themselves. Having an Indigenous person with a disability in a position of power for policy-making decisions was also recommended. Other suggestions included encouraging tribal communities to take the lead in addressing their own biases and harmful behavior towards individuals with disabilities, addressing non-conforming experiences, and holding Talking Circles for elders and leaders to better represent the community. It was also suggested to prepare Indigenous youth with disabilities by educating them on real-world issues and hosting beneficial workshops within their communities. Normalizing and decolonizing people with disabilities was also proposed, along with raising awareness through reports such as the IDAC report. It was emphasized that assisting and educating Indigenous youth is crucial as they are the foundation of their tribes. Encouraging tribal members to attend open state rehabilitation council meetings to self-advocate, and Indigenous youth informing their peers about disabilities to reduce stigma and stereotypes were other ideas.

*“Something that I think would help other youth who may be having a hard [time] understanding how to ask for help, and how to get the help that they need. And everyone uses the word advocacy, but I didn’t hear the word advocacy til I was 17 years old. And I had no idea what it is meant when I first heard it. So even bringing awareness to those words, so that youth and young adults are able to have that voice and use the voice that was fully given so that we’re able to provide whatever supports and resources that they need and that are wanted from them.”*

*– Session 1, IDAC Member #1*

Two individuals expressed the need for local organizations and providers willing to partner with tribal communities to provide services to the tribe and uplift the entire community while providing resources and support for individuals in need.

*“I think educating the outside service providers on what is actually culturally appropriate, what is actually needed culturally in our community to access these services and continue getting the support from them.”*

*– Session 1, Participant 1*

Two participants proposed that state and federal legislation be reviewed to make it inclusive of people with disabilities. Participants also identified a need for expanded legal services to address the legal issues facing Indigenous people with disabilities.

*“They had like legal aid or whatever, but they don’t like take like civil rights cases or things of that nature. And I guess it would be more toward Indigenous disabled people, here and in where I am in [...] because we don’t really have a lot of that here.”*

*– Session 8, Participant 1*

During the discussion, various individuals offered their perspectives on tribal duties and appeals. One participant proposed that tribes prioritize the inclusion and worth of youth with disabilities within their community. Another suggested that tribal resources should be utilized to prevent potentially hazardous activities. Additionally, a participant stressed the importance of tribal behavioral health resources to aid Indigenous students' mental well-being within schools and communities. Lastly, a participant recommended that tribes establish disability advisory councils.

*“So that there are more advocates out there for people with disabilities, that other tribes establish an advisory council [with] disabilities.”*

*– Session 7, Participant 3*

Regarding the internal factors, one of the participants emphasized the significance of focusing on the Indigenous community members who have disabilities and the necessary changes that must be implemented in the system to facilitate their inclusion. Another participant has suggested that Indigenous people with disabilities need to persevere and maintain self-awareness while gaining an in-depth understanding of disability rights knowledge through education.

One participant shared insight as an Indigenous person living in the suburbs of a big city who experiences and sees their tribal community members struggle with housing. They shared the importance of housing for Indigenous people living in urban and rural settings.

# Summary and Recommendations

## ***Summary of Findings***

Based on a review of what was learned from Indigenous people with disabilities, their families and their advocates, the following is a summary of the common themes for improvement:

### ***Indian Health Services (IHS)***

- Access to IHS-covered medical care regardless of location.
- Cultural and disability knowledge training for IHS providers.
- A Disability Advisory Council for IHS.
- Implement kiosks at HIS.
- Implement policies for assisting individuals (accommodations for blind individuals).
- Enforcement of law (i.e., Section 504) Tribal Nations and IHS discriminates against people with disability
- Train IHS medical providers to be able to diagnose disabilities.
- Braille on prescription bottles; QR code on bottles.

### ***General Accessibility Recommendations***

- Providing digital formats of documents (i.e., accessible for blind individuals to use the voiceover functionalities to read to them independently).
- Including the whole family in conversations about support for children with disabilities.

### ***Indigenous Visibility and Knowledge***

- Reimbursement for traditional healing practices (reach out to individual Indigenous communities for helpful services).
- Providers must train in culturally appropriate services (such as tribal-specific resources, medicine people services, ceremonial services, etc.)
- Educating policymakers on reconciliation, decolonizing, and indigenizing (sharing historical trauma and current personal stories).
- Normalize the presence of Indigenous people (to eliminate Indigenous people being fetishized)
- Continue the work of the IDAC to evolve into an organization that can advocate tribal government for changes.
- Increase the number of Indigenous people in healthcare.
- Create tribal scholarships.
- A tribal member as a certified translator.
- Educate medical providers about the equivalence of Indigenous ceremonial practices and medicine to Western healthcare and medicine.
- Cultural safety training for healthcare providers, professors, college administrators, and employers.
- Improve and update education on Indigenous people (starting from elementary school to reduce misinformation, stereotypes, racism, etc.)
- Trauma-informed, culturally safe spaces for healing for Indigenous Veterans.

## ***Health Care***

- Easier access to learning disability specialists.
- Cultural safety training for healthcare providers.

## ***Virtual Accessibility***

- All known resources keep virtual visits available to the public.

## ***Transportation***

- Accessible, affordable transportation option between home and school.
- Access to public transportation.
- Adequate transportation.

## ***Employment/Financial Security***

- Support to maintain employment.
- Financial assistance for parents of children with disabilities.
- Advocacy, assisting people to learn financial literacy and maintaining employment.
- Advocacy, teaching employers how people with disabilities can participate.
- Educating companies and employers about inclusive practices.
- Dignified and accessible jobs for people with disabilities.
- Accessible and affordable food for people with disabilities.

## ***Information Sharing***

- Using all forms of media to disseminate information on disability resources to a larger audience.
- An online resource page available in all communities; leaders share the online directory with community members who are limited to internet access and/or computer literacy.
- Receive information on available Indigenous-specific services to the Native community.

## ***Education***

- Provide better education funding for Indigenous youth and identify the type of education that would be most beneficial for them.
- Researching the root cause of truancy and providing support rather than mindlessly punishing truancy
- Teach coping skills in schools for stress.
- Advocacy experts can teach parents their rights, boosting their confidence to advocate for themselves and their children.
- Encourage schools and families to communicate and compromise; encourage the tribe to advocate for families to be included in decisions and understand their options.
- Habitat for Humanity assists by building housing for educators.
- Encourage children to attend their IEP meetings at a young age.
- Indigenous representation on the State Special Education Advisory Panel.
- Educate parents on the resources and options available to their children (i.e., the benefits of diagnosis and school-based services).

## ***Advocacy, Peer Support***

- Individuals creating a network system for moral support and advice.
- State and tribal agencies advocate for individuals with a disability with an appreciation for the intersection of Indigenous and disability cultures.
- Educating Indigenous youth and young adults on the existence and meaning of the concept of advocacy
- Reframing what it means to be disabled, neurodivergent, etc., to promote resilience and reduce stigma
- Having a disabled person in a position of power for policy-making decisions.
- Encourage tribal communities and members to take the lead in addressing their own biases and harmful behaviors towards disabled individuals to support them better and include them.
- Address non-conforming experiences in tribal communities; hold Talking Circles for elders and leaders to improve community representation.
- Prepare the youth by educating real-world issues.
- Teach children that differences are okay, disabilities are nothing to be ashamed of, and there are resources available to help them adapt to a different way of life
- Assist and support the youth to ensure the tribe will have a strong foundation and future.
- Educate on topics such as disability advocates and their fight for disability rights, recognizing the strength of people with disabilities.
- Self-advocacy, destigmatizing mental health, increasing access to cognitive and behavioral health services.
- Increase awareness and visibility of Indigenous people with disabilities via the IDAC report.
- Encourage Indigenous youth with disabilities to inform their peers about disabilities to reduce stigma and stereotypes.
- Attend open State Rehabilitation Council meetings to self-advocate.

## ***Link Tribes and Surrounding Communities***

- Locate organizations and providers willing to partner with tribal communities by providing services to the tribe.
- Uplifting the entire community while providing resources and support for individuals in need.

## ***Legal***

- Review legislation to make it inclusive of all people with disabilities.
- Available legal services for Indigenous disability issues; services that address civil rights.

## ***Tribal Responsibilities/Requests***

- Tribes can help youth with disabilities feel included and valued within their community.
- Tribal resources can assist individuals in avoiding activities that pose a risk to their lives.
- Tribal behavioral health should support students' mental health in schools and communities.
- Create community-based training facilities for people with disabilities.
- Encourage tribes to establish a Disability Advisory Council for their community comprised of people with disabilities.

## ***Internal Factors***

- Indigenous people with disabilities persevere and are self-aware.
- Indigenous people with disabilities need to have a complete understanding of their rights under

- federal, state, and tribal laws.
- Focus on Indigenous people with disabilities and necessary system changes.

## **Housing**

- Accessible and Affordable Housing within tribal communities.

The process of bringing the IDAC together, developing an approach to the Talking Circles, and gathering information to ensure that a broad cross-section of the communities was reached resulted in meaningful lessons that will guide the IDAC's future work and may be instructive to others.

1. It is essential to be inclusive, diverse, equitable, and accessible from the bottom up.
2. Do not make adverse inferences when an individual chooses not to provide requested information.
3. Approaches, contacts, and conversations must be conducted with genuine respect for all.
4. Native communities tend to be more accepting, respectful, and inclusive of people with disabilities and those who identify as LGBTQIA2S+.
5. Use inherent and cross-community cultural norms, such as an opening prayer, to ground people and to set the tone of the gathering.

## **Commonality of Findings**

In preparing for the Talking Circles, the IDAC team reviewed existing surveys previously conducted to identify the needs of Indigenous people with disabilities. There is a remarkable consistency across the surveys and assessments. For instance, beginning in 2003, the National Council on Disability published a report regarding the issues facing American Indians and Alaska Natives with disabilities.<sup>17</sup> The issues identified in this report are Healthy Living, including Health Care and Recreation, Education, Independent Living, Vocational Rehabilitation and Employment Resources, Assistive Technology, Housing and Facilities, and Transportation. These issues remained when the National Council on Disability updated the report in February 2023.<sup>18</sup> Looking at the broader challenges facing Indigenous communities, the United States Commission on Civil Rights issued a report that was also consistent with the IDAC's findings. This report found that Health Care, Education, Housing, and Economic Development were significant issues that the United States government underfunded despite the obligations to these communities under the trust relationship and treaty obligations.<sup>19</sup> Finally, the World Health Organization developed the Indigenous Determinant of Health framework to evaluate the nonmedical factors impacting Indigenous communities' health and well-being. This framework complements the IDAC findings and supports developing health equity for Indigenous communities.<sup>20</sup> The framework recognizes the impact of colonization on Indigenous communities and its disruption of traditional healing [Health], environments [Housing and Employment], transmission of knowledge and frameworks [Education], and social structures [Community and Government Responsibilities].

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<sup>17</sup> Understanding Disabilities in American Indian and Alaska Native Communities Toolkit Guide, National Council on Disability, August 1, 2003.

<sup>18</sup> Understanding Disabilities in American Indian and Alaska Native Communities Toolkit Guide, National Council on Disability, February 2023.

<sup>19</sup> Broken Promises: Continuing Federal Funding Shortfall for Native Americans, Briefing Before the United States Commission on Civil Rights, December 2018.

<sup>20</sup> International Working Group. "Indigenous Determinants of Health." National Indian Health Board | UNPFII 2023, January 31, 2023. <https://www.nihb.org/UNPFII2023/>.

## Conclusion

The invaluable insights gained from the Talking Circles have shed light on the significant challenges faced by Indigenous individuals with disabilities and their families. The creation of the IDAC was a necessary step in providing a voice to this marginalized group. The report produced by the IDAC serves as a call to action, inspiring further analysis of the challenges facing Indigenous people with disabilities, and an exploration of practical solutions. Additionally, the IDAC urges policymakers to convert these findings into actionable legislation. It is time to recognize and address the unique struggles facing this community, and the IDAC report serves as a crucial tool in doing so.

It is worth noting that the IDAC recognized limitations, with one of the primary limitations being low attendance at the individual Talking Circles. The IDAC was aware of the digital divide, meaning many Indigenous communities lacked access to technology and computer literacy. To address this, the IDAC suggested having hybrid options in the Talking Circles, where an IDAC member would facilitate an in-person Talking Circle within the community while participants can join virtually. Moreover, the IDAC also proposed offering appropriate incentives to participants who joined in person or virtually, such as providing a gas card. Another area for improvement that the IDAC encountered was the challenge of scheduling due to time zone differences. The IDAC initially scheduled the Talking Circles at a different time, but it was not feasible for those not living on the mainland, such as Hawai'i and Alaska. To address this, the IDAC recommended supporting the hybrid option, encouraging the community to engage and build a strong relationship with the IDAC team. The IDAC has put forth a couple of proposals to enhance their procedures. The first recommendation is to switch from Google Forms to SurveyMonkey for registration purposes. This is because Google Forms has restricted capabilities and resources, whereas SurveyMonkey would allow for a more comprehensive analysis of the outcomes. The second suggestion is to reevaluate the language utilized during Talking Circles and in the IDAC report to better align with the objective of indigenizing and reclaiming spaces. The IDAC members firmly believe that modifying the language is crucial to accomplishing this aim.

The IDAC recognizes a concept of pan-Indianism within Medicine Wheels, and some Indigenous groups may embrace it. This means that the report's worldview may only be universally applicable to some Indigenous nations. Nonetheless, the IDAC believes that the report serves as a starting point for gathering additional information and discussing potential solutions to the challenges facing Indigenous people with disabilities. The IDAC has recognized that the report compiled only partially represents some Indigenous nations. To bridge this gap, the IDAC urges Indigenous individuals to take the initiative to conduct further surveys within their communities. This will not only help collect more accurate and comprehensive information but will also ensure that the narrative is told by the people most affected by it. Furthermore, the IDAC acknowledges that not all Indigenous groups embrace the worldview employed in the report. This means there could be variations in how different Indigenous nations interpret certain concepts and principles. Therefore, the report should only be considered a representation of the experiences of some individuals and some Indigenous communities. While more focused surveys may be helpful for individual Indigenous communities to sharpen the focus, the IDAC strongly recommends that the time for assessing the issues facing Indigenous people with disabilities is past. The issues have been identified and are well known from the national to local level. The time has come to begin developing strategies to address these issues.

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