



# Considerations for Improving Services for Native American/American Indian Individuals with Disabilities and Mental Health Concerns

## Note About Use of Terms

*In this fact sheet, we will use the acronym NA/AI for Native American/American Indian, used to refer to the Indigenous people of the United States. Although Native American and American Indian are terms often used interchangeably, individuals have their own preference. For example, someone might prefer a more specific description like Alaska Native. Our recommendation is to use the term an individual prefers.*

## Introduction

Services available for people with disabilities in the United States are used by individuals of various ethnicities and cultures. However, many do not feel like services consider their cultural values and realities. For example, when speaking about government supports available, a NA/AI mother shared, “Cultural norms are not taken into account. It’s very linear thinking, which is far from a lot of people’s lifestyle and the way they do things.” She, like others, wants providers to be aware of their culture so their children can receive the best possible service.<sup>5</sup> Many people may not be aware of Native culture, and there is little research available seeking to understand how NA/AI communities view and define disability. According to data from the CDC and Census, NA/AI people have the highest rate of disability of any racial/ethnic group.<sup>1, 6</sup> It is not completely clear if this higher rate is due to misdiagnoses or because NA/AI individuals are at-risk for experiencing many factors affecting health. Individuals with disabilities are also at a higher risk for experiencing these risk factors. Some of these factors include poverty and limited access to healthcare.<sup>8</sup>

NA/AI people also show disparities related to mental health. NA/AI adults reported experiencing

serious psychological distress 2.5 times more in a month than the general population.<sup>2</sup> Being aware of cultural beliefs and values is important for providers and professionals looking to provide the best service and support they can. Other helpful considerations are what barriers may affect an individual and what other resources could be beneficial. Lastly, we would like to note that like all racial/ethnic groups, there is diversity among NA/AI communities, tribes, and individuals.

## Perspectives Surrounding Mental Health and Developmental Disabilities

In a study seeking to understand how NA/AIs perceive and define disabilities, there were four prominent themes identified. These themes were identified from analyzing conversations about disabilities with people from various tribes across Utah.

### *Disabilities are subjective.*

Disabilities are viewed as subjective and up to the individual to decide if it is a disability. Many NA/AIs agreed having a disability means a person needs more support in particular areas compared to their peers and need help to complete tasks. Some examples of disabilities mentioned were physical disabilities that affect mobility, disabilities that affect hearing and vision, medical conditions that require individuals to be provided a lot of care (cancer, diabetes), and when a person’s ability to communicate is affected, such as by autism. Many viewed disabilities as affecting a person’s ability to learn, such as with Attention-Deficit/Hyperactivity Disorder and learning disabilities. However, there are mixed views on whether mental health struggles are viewed as disabilities with people being about equally split between yes and no. It was noted that mental health concerns, like anxiety, can affect

communication, relationships, and learning. Some feel that hesitation about whether mental health conditions are disabilities comes from how it is not visibly seen and because they appear so common among people today.<sup>3</sup>

### *Disabilities affect a person's sense of belonging.*

NA/AI individuals express recognizing that their cultural teachings and beliefs about disabilities are different from those of mainstream culture. Disabilities are viewed as a gift and does not mean a person is less than others. A quote explaining this well is, "They [people with disabilities] will be showing us something that we're not aware of. They have special gifts, that we don't have, that they are given. So, because of that, we need to just watch and help." Many described it as common practice in their communities to include people with disabilities. Individuals with disabilities are seen as "knowledge keepers" and are important in their communities. However, many have expressed how having a disability can affect belonging in a negative way too. Since not everyone views disability the same, people with disabilities can experience isolation when they are separated from others and inclusion is not practiced. This can happen in various settings, like in school or at work, and among peers, family, and in other relationships. Many shared how they or their family advocated for individuals with disabilities, because unity is an important value and strength of theirs.<sup>3</sup>

### *Action is needed.*

A common topic discussed among NA/AI individuals when talking about disabilities was the need for action. Some of the wanted improvements and changes include improving quality of care and providers' cultural competence. Examples given of what providers could learn about are: "importance of building relationships with Native communities", "being available and genuine", and "the subjective definition of disability." Learning about and implementing this knowledge can help NA/AI individuals feel more comfortable with providers and help them to learn more about what services they can use.

It should be recognized that these themes are interconnected and altogether define perceptions on

disability. To understand one aspect, you need to consider how it is part of a larger experience and each theme affects the others.<sup>3</sup>

### *Individuals with disabilities face barriers to accessing services.*

A theme discussed when defining disabilities in NA/AI communities was how accessing services commonly comes with barriers. This experience can happen in many different ways. For example, people with disabilities can face transportation barriers, long waits for services, and resources are not always available nearby. Another common problem discussed was not knowing how to access services to begin with and simply getting a diagnosis can be a difficult process. This means that NA/AI peoples might be experiencing one barrier after another when trying to access services.<sup>3</sup>

## **Barriers**

There are many factors that affect how accessible services are. Whether services are welcoming, respectful, and responsive to people of various cultures affects accessibility. Another important factor affecting accessibility is proximity, whether services are located near individuals and families who need them. Federal health services for NA/AI, including mental health services, are available through Indian Health Service (IHS) facilities and community health centers. IHS is a part of the Department of Health and Human Services and is the primary federal health care provider and health advocate for NA/AI.<sup>4</sup> The majority of IHS clinics and facilities are located on reservations. This can help with accessibility for NA/AI who live on reservations, but less than a third of NA/AI do. The majority of NA/AI people live in metropolitan areas and access to IHS services is limited. IHS has recognized this challenge and increased funding for initiatives in off-reservation areas. The [IHS Find Health Care tool](#) can be used to find IHS health services nearest your location. Access to health care is also affected by what health insurance someone has and if they have insurance. A greater percentage of NA/AI individuals have public health insurance (42%) or no health insurance (15%) than non-Hispanic White individuals.<sup>7</sup> IHS community health clinics may be a good option for some, because they offer sliding

fee programs and work with people who do not have insurance too.

In a research study using sharing circles, NA/AI individuals shared barriers they experienced which affect NA/AI people with disabilities. Some of the barriers identified included lack of internet access, long waits, and transportation issues. Participants shared how living in rural areas often meant having to travel far distances for services. On top of travel time, they shared how they faced long waits for services- including emergency services. For people with disabilities who may need to travel for services more often, this time adds up. For individuals and families, this means losing time that goes towards other important parts of their lives. Participants also shared how getting a diagnosis is difficult and even getting services they are entitled to through the school is challenging. Some examples provided were not having a local specialist available to make a diagnosis, having to advocate persistently for the school to realize the extent of a child's disability, and waiting years for an accommodation.<sup>3</sup> Many parents learn their child has a disability through the school, and it is often their first time learning about any disability services. When this process is challenging, parents may feel discouraged or even hopeless.

## Recommendations and Cultural Considerations

Participants in the previously mentioned study agreed on some common barriers, but they also agreed on suggestions. A common suggestion brought up was building trust in Native communities. Some suggested ways of doing this included getting to know the people and learning about how to support Native communities. If someone shows that they can be trusted and are unbiased, then NA/AI families can feel more comfortable and willing to let someone in to help their child. Along with getting to know the specific community, professionals should seek to learn more about cultural competence and do so regularly.<sup>3</sup>

Learning about differences between cultures can help professionals better communicate and build rapport with individuals and families. It is important to recognize that a person's values influences their

behavior, communication, and expectation. For example, a professional may be very time-oriented and views it as being respectful or professional. This view and value of time is part of the professional's culture. For someone who is more flexible with time and places more value on connection, the professional's behavior may be seen as curt or uncaring. Eileen, a NA/AI mother of an individual with Down syndrome, said she felt like providers often did not give her son the time or attention he needed. Her advice for providers is to "be human, be compassionate, be really inspired to search out what it means to be [that individual] ...and bring that out. Because most times (...), not very many people spend a lot of attention on them [people with disabilities]. That's what I noticed, which was very, very sad because they need that attention and they've got so much to give."<sup>5</sup> This advice to get to know the individual and what they offer is possibly related to cultural beliefs surrounding people with disabilities and every person's sacredness. Beyond just being aware of an individual and family's culture, another recommendation is the service provider incorporating the client's values and interests into their support and work with them. This can support an individual's development, mental health, and increase rapport and trust.

Lastly, many NA/AI people have expressed not knowing how to begin finding and accessing services for people with disabilities. This shared experience by families means that improving education about what services are available and how they can access them is needed.<sup>3</sup> This can mean increasing the education available or seeing if the information is easily accessible to NA/AI individuals and families.

## Learn More

More research is needed on understanding NA/AI perspectives surrounding disabilities and mental health. One way we can always learn more though is by listening to individuals with lived experience. A lot of the information in this fact sheet comes from a study, interviews, and webinar training with NA/AI individuals. You can learn more by accessing these resources at the following links:

- [Perceptions of Disabilities Among Native Americans within the State of Utah study](#)

- [Eileen Quintana Digital Storytelling Episode](#)
- [An American Indian/Alaska Native Perspective on Mental Health, Disability, and a Greater Understanding of Native Culture webinar](#)

## Contributors

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