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Introduction

Across Indian Country, long-term care facilities run by tribes and American Indian and Alaska Native (AI/AN) organizations offer culturally appropriate care for people within their own communities. Some long-term care facilities provide care for adults with disabilities. Skilled nursing facilities\(^1\) can provide a safe, comfortable setting for people with developmental, intellectual, or physical disabilities who need 24-hour care.

Leadership from three tribal nursing homes provided input on their approaches to caring for residents who have disabilities. Their guidance, which is summarized below, offers insight into successful programs, tools, planning strategies, resident activities, staff training, and approaches to resident advocacy.

While the interviewees offered some general insights about this topic, at the time of the interviews, their facilities housed few adults with disabilities under the age of 55. They recommended gathering feedback from smaller LTSS facilities, such as adult family homes, to develop a clearer picture of successful strategies for caring for adults with disabilities in Indian Country. To supplement their guidance, the second portion of this report summarizes the results of a review of resources and organizations that support appropriate care for people with disabilities. Further investigation of these resources would help produce more detailed guidance for providing long-term care to adults with disabilities in tribal settings.

Interview Findings

Leadership from the following programs shared their approaches to caring for residents with disabilities:

- **Utuqqanaat Inaat Nursing Home**, operated by the Maniilaq Association in Kotzebue, AK
- **Morning Star Care Center**, operated by the Shoshone Tribe of the Wind River Reservation in Fort Washakie, WY
- **Laguna Rainbow Corporation**, operated by Pueblo Laguna in Casa Blanca, NM

This section summarizes their input and highlights examples for each strategy discussed.

Programs, Services, and Tools

The facilities interviewed strive to provide patient-centered care, which honors individual needs and preferences by tailoring equipment and programs to each patient’s unique situation. Utuqqanaat Inaat Nursing Home provides wheelchairs or other adaptive equipment based on the resident’s level of mobility and the severity of the disability. The facility also helps coordinate

\(^{1}\) Skilled nursing facilities provide a high level of medical care through trained professionals like registered nurses
transportation for residents to visit their homes and villages and arranges care and medication for them during their visits.

“Getting to go home and see their people makes for a happier elder. We schedule, transport and make sure that they are going to the doctor, to the optometrist, to the dentist.”

Karen Kyler, Utuqqanaat Inaat Nursing Home

Morning Star Care Center offers counseling, behavioral health services, physical therapy equipment, and group classes. Residents have access to headphones and iPads for musical stimulation and a room where they can quietly rest and refocus.

Planning
Planning for individualized care should begin as soon as a facility admits a new resident. Morning Star Care Center creates tailored behavioral health plans for residents who have developmental disabilities. To develop the plan, the facility convenes with mental health professionals, the resident’s family members, and facility staff to determine how to meet the resident’s needs and ensure their safety and the safety of the other residents.

To plan for care, Utuqqanaat Inaat follows guidelines from the Alaska Department of Health’s Senior and Disabilities Services. The agency provides a psychological assessment of the new resident and informs the facility about the care requirements and expectations for that person, including guidelines on how long the person can stay at the nursing home and the best approaches for treatment.

Resident Activities
Activities and programs that are rooted in culture and community promote holistic health for residents who have disabilities by helping them remain connected to familiar lifeways. Utuqqanaat Inaat employs a full-time activity director who coordinates personalized activities according to preferences, levels of mobility, and culture. Group activities often include traditional food potlucks, bingo, movie screenings, church services, live music, and visits from students at nearby schools.

At Morning Star Care Center, engaging residents in familiar activities and providing opportunities to connect with their communities helps them maintain a high quality of life. The facility also uses culturally based techniques to support resident health, such as horse therapy or music therapy.

Staff Training
To educate all nursing home employees about how to interact appropriately with residents who have disabilities, nursing homes should provide an all-staff training on residents’ individual diagnoses and how those may influence their activity levels and behaviors. For each new hire, Morning Star Care Center conducts staff training that covers individual resident situations and
needs. When a resident with a unique set of needs arrives at the facility, all staff attend training on how to personalize care to honor that person’s needs.

“We do individualized training with staff when they get hired, and we continue that training if needs arrive in the building.”

*Kelly White, Morning Star Care Center*

Partnership with other organizations can support effective training that helps staff understand the needs of each individual as soon as they are admitted to the facility. At the time of the interview, Utuqqanaat Inaat did not have residents under age 55 with disabilities, but indicated that, if they admit a resident who fits this description, they will seek training recommendations from the Senior and Disabilities Services through the Alaska Department of Health. They would also work with the referring branch of the Maniilaq Association, the overarching health and social services organization, to orient employees to the new resident’s unique situation. The facility would also work in close partnership with the entities who fund LTSS, such as Medicaid, to ensure compliance with their regulations and guidelines for caring for people with disabilities.

**Resident Advocacy**

To ensure the safety and dignity of all nursing home residents and advocate for the needs of those with disabilities, the interviewees emphasized the importance of working with a community ombudsman\(^2\) to represent residents’ concerns or employing a dedicated resident advocate. Utuqqanaat Inaat Nursing Home supports resident advocacy through regular visits from a volunteer community ombudsman who the facility can contact at any time to ensure the facility upholds the residents’ rights and acts in their best interest. To provide resident advocacy, Morning Star Care Center created a staff position to focus on addressing resident needs. Further, the facility partners with a social services organization that provides advocacy services.

At Laguna Rainbow Corporation, residents can present their concerns through a formal grievance process. Through the facility’s long-term care ombudsman program, the ombudsman alerts the facility’s board and administration of any resident concerns that are not being met. Since the local community is closely connected to the facility, religious leaders and other community advocates may also carry forward concerns on behalf of the residents. Education about the resources available to people with disabilities is a key element of successfully advocating for residents and connecting them with the services they need.

\(^2\) An advocate who represents community members’ interests and helps them address problems or complaints
Summary of Insights
The program leadership summarized their input with the following insights about caring for people with disabilities.

- Actively seek trainings and online resources to inform staff about best practices for caring for adults with disabilities.
- Compile a list of available resources in the community and build relationships with community programs that support people with disabilities.
- Encourage resident advocates to seek education about available services, resources, and funding mechanisms.
- Network with the entities who fund LTSS, such as Medicaid or Medicare, and ask questions.
- Network with the state department of health division that oversees care for people with disabilities.
- Keep in mind the diversity of residents, as well as the variety of services that may be available to them through the state, tribe, or region, and work to ensure that tribal leaders, providers, and decision makers are aware of the resident’s needs.

Review of the Resources
To supplement the guidance from tribal long-term care facilities, this section of the report presents a high-level summary of resources and organizations that support high-quality care for people with disabilities.

A number of publications offer insight into the experiences of AI/AN people with disabilities and present strategies for how to best provide them with long-term care. Several reports examine the persistent health disparities that AI/AN people face, such as a higher rate of chronic disease, despite having a shorter life expectancy than other races. Other reports and articles describe avenues for financing care for AI/AN people with disabilities, such as Social Security benefits and Medicaid, and how cuts to these health care funding sources affect Indian Country. Several toolkits are designed specifically for tribal communities, including the National Council on Disability’s Understanding Disabilities in American Indian & Alaska Native Communities, which shares suggestions for improving services, providing protections, and leveraging resources for people with disabilities in tribal communities.

Many organizations provide research, resources, and advocacy for people with disabilities. For example, the National Council on Disability offers broad information about applicable laws, regulations, policy guidance, barriers, promising practices, and models related to LTSS. Organizations that focus on American Indians and Alaska Natives or serve areas with high
populations of AI/AN people may be especially helpful in providing information to support tribal LTSS programs in caring for people with disabilities.

**Conclusion**

Tribal long-term care facilities provide culturally appropriate, community-based care for elders and adults with disabilities. Other tribal programs have successfully supported residents with disabilities through individualized programs and tools, personalized planning, staff training, and advocacy for residents’ needs. In addition, many resources and organizations offer insight into the best approaches to caring for AI/AN people with disabilities. Examination of the available resources, as well as interviews with adult family homes and other small tribal LTSS facilities, would help strengthen recommendations for providing long-term care for people with disabilities in Indian Country.