



Department of Health & Human Services, Centers for Medicare & Medicaid Services

LTSS Research:

Improving Care for Adults with Disabilities in Indian Country

Highlights from the Field

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SAIL Disability Network of the Upper Peninsula

“Being a Center for Independent Living, our goal is to serve the individual with what they want.”

Kristin Williams, Native American Services Coordinator, SAIL Disability Network of the UP

Program Description

The Stay Active and Independent for Life (SAIL) Disability Network of the Upper Peninsula (UP), in Marquette, MI, is a community-based, non-profit organization that provides a wide variety of programs and services to individuals with disabilities in Michigan’s UP. SAIL Disability Network of the UP is the only organization designated as a Center for Independent Living¹ (CIL) in the UP. As a CIL, the program provides five core services designed and operated by people with disabilities. The services are:

- information and referral (case management provided by social workers);
- peer support;
- individual and systems advocacy;
- assistive technology, education, and training that support independent living skills development, and
- assistance with transitions from care facilities independent living settings.

SAIL Disability Network of the UP received the Native American Independent Living Demonstration Project grant from the Administration for Community Living (ACL) in the fall of 2018. The program serves American Indian and Alaska Native (AI/AN) people with disabilities in the UP, and through the ACL funding, they created a dedicated program to serving the five tribal communities in the UP. SAIL Disability Network of the UP staff are in the planning and hiring phases for the program.

Programming Tailored to Tribal Communities

“Each of the tribal communities are extremely different. Their needs are different. Their resources are different... I am learning about what services they already have,

¹ ACL provides grant funding to non-profit organizations through the Centers for Independent Living program. To receive funding and designation as a CIL, organizations must meet several criteria and standards of excellence. They must be, “consumer-controlled, community-based, cross-disability, nonresidential, private, nonprofit agencies who provide independent living services.” (Administration for Community Living. (2018). Centers for Independent Living. Retrieved from [https://acl.gov/programs/aging-and-disability-networks/centers-independent-living.](https://acl.gov/programs/aging-and-disability-networks/centers-independent-living))



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what is and isn't working, and where they see [SAIL Disability Network of the UP] fitting in."

Kristin Williams

SAIL Disability Network of the UP staff are engaging with tribal communities in the UP through focus groups and short questionnaires to determine which services are a good fit for each community. The program is also in the process of hiring two Native staff members to work closely with tribal communities and become experts on their designated tribal areas. The goal is to tailor services to the needs of each community, not to duplicate any services.

A Focus on Person-Centered Care

"We have a person-centered approach, and we try our best to support individuals in their own choices to live the most independent life that they can... Other agencies without this [person-centered] focus tend to do what they think is best, but it might not be what the individual wants."

Kristin Williams

SAIL Disability Network of the UP practices a person-centered approach, which encourages each client to make their own decisions regarding their living situation and the level of assistance they receive. A person-centered focus is a departure from the often paternalistic approach of many organizations that support individuals with disabilities. Staff are optimistic that their focus on empowering individuals with disabilities will be a good fit for tribal communities in the UP.

Recreation Program for Adults with Disabilities

"Our recreation program is one of our biggest programs for adults. We offer classes, whether it's nutrition, cooking, or art, for all abilities. The recreation program provides a social component."

Kristin Williams

SAIL Disability Network of the UP's recreation program is popular with adults in the program because it provides a wide variety of activities for individuals with disabilities and an important social component to their care. The recreation program benefits the psychosocial needs of adults with disabilities, an important component of overall health and wellness that can be overlooked in providing care for adults with disabilities.



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Alpine Resource, Inc.

“We provide community-based services, such as programming in day programs and group homes and respite care, and attendant care... A lot of our folks have multiple diagnoses: cognitive issues, as well as epilepsy, as well as autism. We have people on wheelchairs and walkers”

Lori Gelvin, Associate Director, Alpine Resource, Inc.

Program Description

Alpine Resource, Inc., is a non-profit organization, founded in 1987 and located in Flagstaff, AZ. The organization supports individuals with disabilities in the tribal communities of northwest Arizona, including the Hopi Tribe and the Navajo Nation. Most of Alpine Resource’s clients are adults ranging in age from 18–70 with a wide variety of physical and cognitive disabilities. Alpine Resource provides community-based services, including:

- respite for caregivers;
- attendant care;
- programming in day and group homes, including educational and recreational activities;
- transportation to medical appointments;
- assistance scheduling medical appointments; and
- goal setting and individual service plan meetings.

The program serves a population with complex medical needs, who frequently have co-occurring disabilities, in rural parts of northwest Arizona. The staff respond to these challenges with compassion, flexibility, and a commitment to helping individuals with disabilities in these remote tribal communities.

Commitment to Culturally Informed Services

“All of our staff are Native American... They live in the communities; speak, or at least understand, the Native languages; and participate in events, like powwows and school events. We really listen to our staff and the suggestions that they may have, because I consider them the experts.”

Lori Gelvin

Alpine Resource staff are proud of their deep connections in the tribal communities they serve, which support them in providing culturally informed services that are tailored to the unique needs of their



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clients. Through their in-depth knowledge of the tribal communities, staff are aware of community events, like powwows, where they can set up tables. They use these opportunities to promote Alpine Resource and identify individuals with disabilities who need supportive services.

Learning to Serve an Aging Population

“Our population is like anybody else across the nation. We seem to be aging. We're running now into challenges with type 2 diabetes, heart disease, respiratory conditions, mobility, decreasing vision, and dementia. So, we sent staff to a training to learn about this population.”

Lori Gelvin

Alpine Resource staff are adapting their services to fit the needs of an aging population. Staff are encouraged to attend trainings to expand their skill sets. To learn more about how to best serve older adults with disabilities, several staff members recently attended an in-person training in Phoenix, AZ.

Retention of Engaged Staff

“I think our staff members are awesome. They serve and support because they want to make a difference in their community. A lot of them have worked for us between 10 to 30 years. Our people stay a long time, and that experience is important.”

Lori Gelvin

Due to their commitment to compassionately serve tribal communities in northwest Arizona, Alpine Resource has successfully retained high-performing, engaged staff. The staff at Alpine Resource are essential to the organization's success working with adults with disabilities in remote tribal communities. Long-term staff bring significant institutional and community knowledge.

North Intertribal Vocational Rehabilitation Program

“We're not just another social services program. We focus on rehabilitation ... We're here to help individuals learn about their disability so they can live independently.”

Jana Finkbonner, Director, North Intertribal Vocational Rehabilitation Program



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Program Description

The North Intertribal Vocational Rehabilitation Program (NIVRP), operated by the Stillaguamish Tribe, serves the Nooksack, Sauk-Suiattle, Stillaguamish, Swinomish, Tulalip, and Upper Skagit Tribes in Skagit, Snohomish, and Whatcom counties in Washington state. NIVRP assists adults who are enrolled tribal citizens in these areas and cannot obtain or maintain employment due to a permanent disability. The majority of NIVRP's clients have mental health or substance use disorders and a co-occurring disability. NIVRP helps adults with disabilities gain and maintain employment and live more independently.

Services include:

- on-site job coaches,
- disability evaluations and assessments,
- transportation services,
- medical referrals,
- mental health counseling,
- assistance connecting individuals to cultural healing processes, and
- assistance with independent living activities, including household chores.

Connecting Clients to Cultural Healing Practices

“Some individuals dealing with mental health issues, such as PTSD or depression or anxiety, ask to get reengaged in their community and utilize cultural services. So, we've helped people get connected with language classes and basketry. We do a canoe journey up in this area, so we've helped people with services to get to that canoe journey.”

Jana Finkbonner

NIVRP's holistic approach to vocational rehabilitation includes connecting clients with their tribal communities and helping them access cultural activities and healing practices. NIVRP staff understand the important role that culture plays in health, particularly in tribal communities. The program recognizes community engagement and cultural practices as critical components for stable employment and independent living for their clients.



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Client Monitoring and Follow-Up

“They work for 90 days and then we talk with them about closing their file and then once we close their file, we don't just forget about them. We check in on them periodically, and then they can come back and do something called post-employment services, where we provide them with short-term services that help keep them employed.”

Jana Finkbonner

NIVRP maintains communication with clients once they have obtained and maintained employment. The program provides post-employment services to help clients maintain and thrive in their employment. These services include:

- mental health and substance use recovery services;
- assistance obtaining necessary job training, including CPR and first aid; and
- assistance obtaining health insurance, auto insurance, and auto repairs.

Successful Collaboration with the State

“Washington state has a really unique relationship with tribes, so we've used that to our benefit to work closely and collaborate with the state [division of vocational rehabilitation] offices.”

Jana Finkbonner

NIVRP staff maintain a close relationship with the Washington State Division of Vocational Rehabilitation and feel that they can voice and address the concerns of the tribal communities they serve. NIVRP attends two annual meetings with the state and other tribal vocational rehabilitation programs, which encourages dialogue about tribal concerns and closer collaboration with the state program.



Program Contact Information

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