



PRIORITY 1 - REDUCE THE WAITLIST

- Medicaid's standard coverage mandates institutionalization for people with intellectual and developmental disabilities (IDD) instead of home and community-based services (HCBS). Services for individuals who live at home or on their own, or who want to be served in their home communities are not required.
- The State of Alaska Automated Budget System, Final Auth 19 report recognizes that institutional care is much costlier than HCBS for people with the same level of need led to the creation of federal Medicaid rules, which *waive* the requirement that services be provided in institutions and allow states to establish Medicaid HCBS waiver programs. The average annual cost per person with an IDD waiver is \$88,769 compared to an average annual cost of \$214,423 for institutional placement.
- Medicaid allows States to maintain waiting lists for HCBS waiver services when demand exceeds resources. *In Alaska, only individuals with IDD are impacted by a waitlist.* They wait - sometimes for years for their number to be called.
- In FY16, SDS cut the number of annual draws from the waitlist from 200 to 50. As a result:
 - ✓ The number of people on the waitlist grew from 535 in FY16 to 702 (9/19)
 - ✓ 14 individuals are in out-of-state institutions and 13 children and youth are being served in Residential Psychiatric Treatment Centers (11/19)
- The longer people sit on the waitlist, the more costs increase.
 - ✓ Young people sit at home and lose the skills they developed in school
 - ✓ Family members neglect their own health and forego income trying to "do it all,"
- Individuals and families are not asking for a handout; by the nature of their disabilities, individuals with IDD require individualized, comprehensive and life-long services to live successfully in the community.
 - ✓ Families contribute to the cost of care for their children with IDD – far beyond what they contribute to the care of their children without a disability
 - ✓ More than 70% of individuals with IDD live at home with a family member, many of whom are aging and may need long-term services and supports themselves
- **Return on Investment:** Federal law says *costly institutional services must be provided if requested by the individual and/or family.*
 - ✓ Average annual cost per IDD waiver person is \$87,718, compared to \$171,904 in nursing homes, \$214,423 in out-of-state institutions and \$531,312 at the Alaska Psychiatric Institute

- **Offsets and Cost Savings Recommendations:**
 - ✓ Using technology to reduce the need for direct staff support
 - ✓ Establishing Medicaid waiver billing codes for 1) companion services; and 2) a semi-independent living option that allows some shared staffing supports
 - ✓ Developing an alternative approach to funding supported employment services;
 - ✓ Fully implementing the durable medical equipment re-use and the Alaska ABLE programs

RECOMMENDATION: REDUCE THE WAITLIST

As of January, 2020, 730 Alaskans with disabilities are on the waitlist for waiver services. Only 50 people each year are selected from the waitlist, when it used to be 200. Savings from Medicaid Reform SB74 (2016) are available to help Alaskans who wait.

- **Our ASK:** Use the savings from SB74 to increase the waiver waitlist draw to a minimum of 100 people per year, in addition to filling open slots from death or moving out of state, to make sure the baseline of people getting services goes up by 100 people per year. Work with stakeholders to develop updated criteria for waitlist draws.



PRIORITY 2: STABILIZE SERVICE INFRASTRUCTURE FOR INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES WITH PREDICTABLE, STABLE POLICIES AND FUNDING

- 2,048 Alaskans are currently being served through Alaska's home and community-based services (HCBS) system for individuals with intellectual and developmental disabilities. These services are essential for people with IDD to live meaningful lives in homes and communities of their choice. The State of Alaska, Division of Senior & Disabilities Services (SDS) contracts with provider agencies statewide to help people with daily activities like eating, bathing, dressing, finding and keeping employment, and connecting with friends and neighbors.
- Over the past few years, Alaskans, including individuals with IDD, family members, service providers, state agency staff and community members came together to develop the Developmental Disabilities (DD) Shared Vision for Alaska. SB174, sponsored by Senator Peter Micciche, placed the Shared Vision's inspirational language within state statute. It provides the lens for how services are provided throughout the state, ensuring that individuals with DD receive services that lead to meaningful person-directed lives.
- The DD Shared Vision, as defined in state statute is: *Alaskans share a vision of a flexible system in which each person directs their own supports, based on their strengths and abilities, toward a meaningful life in their home, their job and their community. Our vision includes supported families, professional staff and services available throughout the state now and into the future.*
- As a result of the investment in Alaska's HCBS system, in 2007 Alaska was ranked second in the nation for inclusionary outcomes for people with IDD and as a leader in moving away from costly institutional placements. Unfortunately, this is no longer true. Alaska's system of HCBS services for individuals with IDD now ranks #40 in 2019.
- In FY16, SDS cut the number of annual draws from the waitlist from 200 to 50. As a result, the number of individuals on the waitlist grew from 535 in FY16 to 702 as of September 2019. Individuals who are selected for services often wait months before starting services. Meanwhile millions of dollars originally allocated to the SDS service system are used by other Medicaid programs.
- DD Community Grants funds were previously used to ensure timely access to services and serve individuals on the waitlist. However, in FY18, SDS starting using grant funding to draw down 50% federal funds through the Individual Supports Waiver (ISW) Program implementation has been slow; as of September 2019, 269 individuals are receiving services through the ISW and 309 plans of care are still in process.
- Service limitations established in FY18 on community based services such as day habilitation were implemented as part of Medicaid reform. As a result, people are left with reduced community access, services are not as flexible and are being provided based on need as required by federal law. Providers struggle to continue offering these services, even at reduced levels during a workforce shortage.

- Almost 99% for funding for HCBS comes from state and federal Medicaid dollars, which IDD providers cannot negotiate. Unlike some other federal programs, the rates are fixed. IDD providers cannot charge individuals and families for their services, and therefore, have no way to pass on increasing costs to their customers.
- Current rates are insufficient to support wages needed recruit and retain a qualified direct support workforce, due to increased costs associated with compliance and audits stemming from increased regulatory burdens. Legislative denial of regulatory cost-of-living increases in past years have caused rates continue to lag behind the rate of inflation while the cost of doing business continues to rise. According to national data, turnover costs average \$4,872 per person. And these costs do not capture the most important impact of employee turnover: service disruption for individuals with IDD.
- Existing rate methodologies are out of alignment with the current cost of delivering services and some services such as respite care and supported employment are reimbursed at rates below the cost of delivery. In addition, a number of new federal regulations and state-level policy initiatives have resulted in increased costs to providers without any additional funding.
- Over the past 7 years, Key Coalition of Alaska, the Governor’s Council on Disabilities and Special Education and the Alaska Association on Developmental Disabilities have provided a variety of cost savings and offset recommendations to SDS, the Department of Health & Social Services and the legislature. Not only will these recommendations save money, they have the potential to address the major service infrastructure issues identified above, address unmet needs and ensure essential supports and services are available to help Alaskans with IDD live successfully at home and in the community.
- To date, the vast majority of these recommendations have not been implemented or discussed in much detail.
- The bottom line: Alaska’s IDD service delivery system has reached a tipping point and is close to losing providers, especially in rural areas. The DD Shared Vision is **not** being realized. If the system infrastructure issues identified above are not addressed, providers will continue to face difficult decisions with compounding negative impacts. These include scaling back on services, employee wages and benefits, or both as some providers have already done, leading to crisis-producing consequences for the individuals they support.

RECOMMENDATIONS:

Priority 2: PREDICTABLE, STABLE POLICIES AND FUNDING

The DD Shared Vision, through SB174 in 2018, describes a flexible system in which each person directs their own supports based on their strengths and abilities, toward a meaningful life in their home and community.

Our current system does NOT provide predictable, stable funding, or a structure that supports the DD Vision.

Our ASK: Bring SB174, the DD Vision, to life by reinvesting the cost savings from SB74 into new and existing waiver services that fulfill the vision for Alaskans with disabilities.