

## Overview of Alaska's Developmental Disabilities Service System

### What are Developmental Disabilities?

Developmental disabilities include a diverse set of conditions that are recognized at birth or during childhood and alter the usual course of development. Common developmental disabilities include but are not limited to Down syndrome, intellectual disability, autism and cerebral palsy. These conditions have a wide array of physical and mental symptoms, which often make it difficult for them to obtain employment, live independently or complete activities of daily living such as eating, bathing and toileting without assistance. By the very nature of their disabilities, they need comprehensive, long-term services over their lifetimes to be active, productive, contributing members at home and in the community.

### How are Services Funded?

Funding for Medicaid Home and Community-Based Waivers is located within Senior and Disabilities Medicaid Services (Component 2662), Medicaid Services (RDU 595) – Grants, Benefits (77000). Some individuals receive services through Community Developmental Disabilities Grants (Component 309, Senior and Disabilities Services 487 – Grants, Benefits 77000, which is being phased out and replaced with the Individual Supports Waiver (ISW), starting March 1, 2018; the ISW Senior and Disabilities Medicaid Services (Component 2662), Medicaid Services (RDU 595) – Grants, Benefits (77000)

### What is the Intellectual & Developmental Disabilities Waiver Program?

Home and Community-Based Services (HCBS) programs are Medicaid programs authorized by Title XIX of the Social Security Act that allow services to be provided in the home or local community for individuals who would otherwise require costly institutional care. These programs waive the requirement that services be provided in institutions and serve a variety of targeted populations, including individuals with intellectual and developmental disabilities.

The Intellectual & Developmental Disabilities (IDD) Waiver is administered by Senior & Disabilities Services, which is located within the Department of Health & Social Services. It covers services for children and adults with IDD. Services are based on the needs of each individual, including but not limited to services such as supported employment, in-home supports, supported living, community inclusion (day habilitation) and respite care.

### Do Waiver Services Save the State Money?

By federal law, costly institutional services **must** be provided if requested by the individual and/or his family. Eliminating the Medicaid waiver programs “would ultimately cost the State of Alaska hundreds of dollars in additional spending annually”, according to Legislative Research Service Report 16.44, February 2016. In particular, participants in the HCBS program, by definition qualify for institutional level of care under Medicaid rules... those expenses are still less than half the cost of nursing home or intermediate care facilities for those with IDD.

In addition to direct costs, its elimination would “generate a great deal of demand for long-term care facilities on a state-wide basis that is already operating near capacity.” “... the absence of Medicaid programs designed to keep people in their homes could force the state to directly participate in the construction and administration of long-term care facilities with capital and operating costs potentially reaching hundreds of millions of dollars.”

### **Do Waiver Services Work?**

Alaska’s HCBS service delivery system works. Hundreds of Alaskans with IDD are living productive, meaningful lives in the community as a result of the services they receive.

- **Over 41.4% of individuals served are employed or working toward employment compared to 28.6% nationally** (Alaska Department of Health and Social Services, Senior and Disabilities Services, Research and Analysis Section, as of 12/16 and Governor’s Council on Disabilities and Special Education Press Release 1-17)
- **47% of individuals served live on their own or with their families** (Alaska Department of Health and Social Services, Senior and Disabilities, Research and Analysis Section, as of 12/16)
- **Adults age 18 to 49 with developmental disabilities receive an average of 27 hours per week of unpaid support from family and friends** (*Caregivers of Younger Adults: A Focused Look at Those Caring for Someone Age 18 to 49*, NAC and AARP Public Policy Institute, 6-16)

### **What is the Waitlist?**

Medicaid allows States to maintain waiting lists for HCBS waiver services when demand exceeds resources. Of the four current waivers, only the waiver for Individuals with Developmental Disabilities (IDD) has a waitlist. As of December 6, there were 739 individuals with intellectual disabilities on the Developmental Disability Registry (waitlist).

Some of the individuals on the registry are currently being served through Community Developmental Disabilities Grants which is being phased out and replaced with the Individual Supports Waiver (ISW), starting March 1, 2018; the ISW has capacity to enroll 600 individuals.

In FY16, Senior & Disabilities Services (SDS) cut the number of annual draws from the DD Registry (waitlist) for the IDD waiver from 200 to 50, which means individuals and families have to wait even longer to get needed services.

## What is the Return on Investment in Reducing the Waitlist?

The longer the 739 individuals sit on the waitlist, the more the cost to the State increase. Without supports, young people sit at home and lose the skills they developed during their school years. Family members neglect their own health and forego income trying to “do it all,” especially as they and their loved ones face the challenge of aging.

- Cost savings to the state: As previously discussed, HCBS costs considerably less than services provided in institutions. **Note:** services **must** be provided in costly institutions if requested by the individual and/or family even though most families would prefer to keep their children at home or living close by in the community.
- Increased family income: Having a child with an IDD makes it more likely a parent will reduce his or her work hours or leave the workforce entirely. (*Stabile, M and Allin, S. (2012). The economic costs of childhood disability. The Future of Children, 22(1):65-96*)
- Improved Caregiver Health: Elderly caregivers without adequate supports are 63% more likely to die within a four-year period compared to non-caregivers. (Scults, R., Beach, S.R. (1999). Caregiver as a risk factor for mortality: The caregiver health effects study, *Journal of the American Medical Association, 282*(23): 2215-19)
- Increased Employment and Productivity: Most adults with IDD want to be employed and support themselves financially. Research shows that waiver-funded supported employment services result in more job placements, higher wages and work hours per week. (Nord, D., Luecking, R., Mank, D., Kiernan, W, and Wray, C. (2013) The state of the science of employment and economic self-sufficiency for people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities, 51*(5): 376-84

## What are Some Recommendations for Reducing the Waitlist?

Services for Alaskans with IDD have already been cut significantly. Families also contribute to the care of their children with IDD—far beyond what they contribute to the care of their children without a disability. In many families, out-of-pocket costs to care for a child with developmental disabilities has been estimated at \$8,000 annually. (*Stabile, M and Allin, S. (2012). The economic costs of childhood disability. The Future of Children, 22(1):65-96*)

Recommendations for reducing the waitlist include:

- Pass a “Alaska fiscal Plan” that includes using the Permanent Fund through POMV as basis for a long-term fiscal plan and creating new revenues
- Implement Key Coalition recommendations for reducing costs, including technology, companion services and semi-independent living to the mix of allowable services