



## **ERADICATE THE WAITLIST FOR DEVELOPMENTAL DISABILITIES SERVICES**

- The federal government allows states to maintain waiting lists for Medicaid-funded home and community-based services when demand exceeds resources. *In Alaska, only individuals with intellectual disabilities (IDD) wait for services – even though this is the population with some of the most significant needs.* The waitlist in Alaska, called the “Registry”, is a “rated” system. Those in crisis receive a higher score than those with natural supports such as family. As such a young adult with Down Syndrome living currently with family but needing support to live more independently may “wait” for 10 years or more to be “drawn” for services
- Alaska was drawing 200 individuals with IDD annually from the waitlist until FY16, when the number of draws was reduced to 50 annually. *As a result, over 800 Alaskans with IDD are waiting for services today.* The longer they sit on the waitlist, the more costs increase. Without supports, young adults sit at home and lose the skills they developed in school. Family members neglect their health and forego income trying to “do it all,” especially as they and their loved ones face the challenge of aging.
- Medicaid is the major source of funding for long-term services and supports provided in home and community-based settings to Alaskans with intellectual and developmental disabilities (IDD).
- Medicaid is a joint federal-state entitlement program primarily providing medical care to low-income Americans. States must provide a number of mandatory services, one of which is institutional care for individuals with intellectual and developmental disabilities (IDD).
- However, individuals with IDD do not want to live in institutions. They want the same opportunities that every American wants: to thrive, not just survive. They want to live in their own homes, in communities of choice, and make decisions about their daily lives; they want to go to school, attend church, work and participate and contribute fully in their local communities.
- The federal government allows states to waive the requirement that services be provided in costly institutions. States have substantial flexibility to design their programs within broad federal requirements related to eligibility, services, program administration, and provider compensation. The Medicaid program provides states with many options to increase the availability of home and community-based services while controlling costs.
- Alaska uses the waiver option to offer home and community-based services to the following groups: children and adults with IDD, adults with physical and developmental disabilities, children with complex medical conditions, and seniors and adults with physical disabilities. *Only individuals with IDD wait for services.*
- Individuals and families are not asking for a handout. By the very nature of their disability, individuals with IDD require individualized, comprehensive and life-long services in order to live successfully in the community. *In addition, 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.*

**RECOMMENDATION:** The Key Coalition has been advocating for over 30 years to *eradicate* the waitlist, giving people with disabilities access to needed services. Enhanced access will result in long-term cost savings to the State of Alaska by providing services early on and keep people in their home communities rather than in costly out-of-state institutions, Alaska Psychiatric Institute or jail.