REDUCE THE WAITLIST FOR DEVELOPMENTAL DISABILITIES SERVICES

- Funding for Medicaid Home and Community-Based Waivers is located within Senior and Disabilities Medicaid (Component 2662), Medicaid Services (RDU 595) – Grants, Benefits (77000). A recent review of Medicaid Services Trends from FY 16 (Actual) to FY19 (Budget) clearly shows that since implementation of SB74 in 2016 targeted at Medicaid reform, Senior and Disabilities Services (SDS) has controlled costs the best. By reducing the number of individuals drawn from the waitlist annually, implementing service caps, increasing utilization control and refinancing State grant fund to maximize Federal participation, SDS's budget only grew by 4.5% compared to 29.6% across all Medicaid Services (Adult Preventative Dental, Behavioral Health Services, Heath Care Services and SDS). During that same time period, the number of people with IDD waiting for services increased by 447.

- Medicaid allows States to maintain waiting lists for home and community-based waiver services (HCBS) when demand exceeds resources. In Alaska, only individuals with intellectual/developmental disabilities (IDD) are impacted by a waitlist; this is the population with some of the most significant needs. In FY16, SDS cut the number of annual selections (draws) from the waitlist from 200 to 50; as a result, the number of people on the waitlist has grown from 535 in FY16 to 629 in FY17 to 739 in FY18 to 982 on January 2, 2019 and the number of individuals receiving services in much more expensive options such as out-of-state institutions or the Alaska Psychiatric Institute has grown.

  - Note: Costs per person average $87,718 for those served within HCBS, compared to $135,924 in nursing homes, $186,909 in out-of-state institutions. Alaska Psychiatric Institute average cost per person is $531,312 (Office of Rate Review – Oct. 2017).

- The longer people sit on the waitlist, the more costs increase. Without supports, 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,” especially as they and their loved ones face the challenge of aging.

- 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 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. Out-of-pocket expenses has been estimated at $8,000 annually on top of all ordinary expenses associated with raising a child. (Stabile, M. and Allin, S. 2012. “The economic costs of childhood disability,” The Future of Children 22 1:65-96)
**Return on Investment:** Federal law says **costly institutional services must be provided if requested by the individual and/or family.** According to Legislative Research Report 16.44, February 2016, if individuals are served in home and community-based settings, “those expenses are still less than half the cost of … intermediate care facilities (institutions) for those with IDD. The report also concludes the state would be required 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.

**Offsets:** Over the past 4 years, the Governor’s Council on Disabilities and Special Education and Key Coalition of Alaska have submitted cost savings recommendations to the State, including 1) using technology to reduce the need for direct staff support; 2) establishing a Medicaid waiver billing code for companion services; and 3) establishing a billing code for the semi-independent living option that does not require 1:1 staff supports. Other recommendations are to develop an alternative approach to funding supported employment services; and fully implementing the durable medical equipment re-use program and the Alaska ABLE program.

**RECOMMENDATION:**

Increase the number of annual selection (draws) from the Developmental Disabilities Registry (waitlist) from 50 to 100, which 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 out-of-state institutions.