



THE STATE
of **ALASKA**
GOVERNOR BILL WALKER

Department of Health and Social Services

GOVERNOR'S COUNCIL ON DISABILITIES
& SPECIAL EDUCATION
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Re: Reductions in annual waiver draws from the DRRR "waitlist"

The Governor's Council on Disabilities and Special Education (the "Council") fills a variety of federal and state roles, including serving as the State Council on Developmental Disabilities (SCDD) under the Developmental Disabilities Assistance and Bill of Rights Act. As the state Developmental Disabilities Council, we work with Senior and Disabilities Services (SDS) and other state agencies to ensure that people with intellectual and developmental disabilities and their families receive the services and supports that they need, as well as participate in the planning and design of those services. One of the duties of the state Developmental Disabilities (DD) Council is providing comments on proposed recommendations that may have an impact of individuals with intellectual and/or developmental disabilities and their families.

The Council appreciates the opportunity to provide input on SDS's proposed reduction in annual draws from the Developmental Disabilities Registration & Review (DDRR) for Medicaid waivers. In reducing the number of applicants drawn from the DRRR from 200 per year to only 50 per year, the Council has serious concerns that this change will adversely affect the quality and availability of services to Alaskans who experience intellectual or developmental disabilities (IDD). Notably, the Council feels that by not keeping up with the annual demand for waiver services, this change will increase the length of time people spend waiting for services, cause them to experience difficulty in accessing services that will increase their needs, and may not actually save the state money in the long run. We conclude our remarks and comments with several cost-saving solutions that may help alleviate these concerns.

Increased Length of Time Spent Waiting for Services Has Trickle-Down Effect. An annual draw of 50 applicants per year does not keep up with the current demand in our state, since approximately 200 babies (or 1.8% of all births) are born each year that may experience intellectual or developmental disabilities (Gollay & Associates, 1981; State of Alaska, 2012). By not keeping pace with demand, this reduction will result in several subsequent changes that will exponentially and adversely affect the people we need to serve and their families, as follows:

- 1) This reduction in annual draws will result in a significant increase in time spent waiting on the DRRR to receive services. Because the DRRR wait time currently averages 3.5 years, the proposed reduction in annual draws will result in an average wait time of closer to 13 years;
- 2) This will then result in people applying for the DRRR much earlier because they will be expecting to wait for nearly 10 additional years, resulting in an increased number of people on the DRRR, overall;
- 3) Waiting longer to receive essential services will then yield incredible financial stress on families. In order to provide care, it is likely that parents and caregivers will be forced to stay home from work, resulting in greater likelihood of family poverty and Medicaid utilization; and

- 4) Without access to waiver services, the burden will fall to caregivers. It is well-documented that caregivers experience significant mental and physical health declines when providing extensive care for individuals with IDD (Elliot et al, 2003; Magana & Smith, 2006). These deteriorating health experiences result in greater service utilization for the caregivers, rather than the individual with the disability, merely shifting the burden of Medicaid costs elsewhere within the system.

People Will Experience Increased Difficulty Accessing Services. Currently, agencies in Alaska seem to be prioritizing individuals with waivers over those who have developmental disability grant funding, due to the higher needs of waiver recipients. STAR coordinators and other professionals working to get services for individuals have reported to the Council that it is more difficult to find providers willing to accept grant funding. This problem will only be intensified as more people are waiting on the DRRR for a longer length of time, which will then increase demand for DD grants. Grants are not a great solution for people with high needs on the DRRR regardless, as they limit the number of service hours and have an annual cap. The DD grant system will be forced to prioritize people with the highest needs, further marginalizing others with service needs on the DRRR. This problem is further aggravated in rural areas without access to services. As much of our state does not have enough qualified professionals, travel is often required, which DD grants do not cover. This further marginalizes our rural population with service needs. When people are not getting services, they are at increased risk of homelessness, unemployment, and engagement with the justice system (Loeber & Farrington, 2001).

These Reductions May Not Save the State Money. As mentioned above, rather than saving money, the DRRR reduction in annual draws just shifts it to a different pot of money, from waivers to grants. Additionally, decreasing the number of draws will not save the state money if eligible families request services provided in an intermediate care facility because the longer wait time on the DRRR has intensified their needs. Federal law requires the State of Alaska to fund these services, which are much higher cost than those provided in the community (\$120,000-\$200,000 compared to an average cost of a waiver at \$75,000-\$85,000). In addition, there are no intermediate care facilities in Alaska. This tears families apart and erases all the great work of the *Bring the Kids Home* initiative (Office of the Commissioner, 2013).

Cost-Savings Solutions. It is imperative that agencies like the Governor's Council help identify cost-saving measures in the DD service delivery system. By finding other ways to cut the budget and save money, the Council hopes that SDS can find ways to eventually restore the annual DRRR draws. To that effect, we have some suggestions:

- 1) Consider redesigning the Plan of Care (POC) form so it is less burdensome and lengthy to complete. SDS could use a shortened POC form in interim years based on what has changed since the last POC review, similar to the process of Level of Care (LOC) determinations. This way, new POC forms can be created every 3-5 years, reducing workload and costs. Likewise, the LOC process could be further streamlined by extending interim years for those participants who have a situation that is highly unlikely to change. Since ICAP assessments are so time-intensive, anything that can be done to lessen the number of ICAPs required annually will equate to greater savings of staff and resources.
- 2) The Council strongly recommends frontloading services by increasing access to early intervention. This increases functionality early in life so that service needs are decreased later in life. For every \$1 spent on early intervention and prevention efforts, the state saves more than \$7, for a benefit-cost ratio of 7.16 (Schweinhart, 1993).

- 3) Anything that can be done to move the control of money and resources to the family or caregiver will help control costs. It is problematic that families do not know the true costs of services. Many caregivers would shop for less expensive alternatives, or reduce using things they think are over-priced, if given the opportunity to do so. To this effect, the Council also suggests providing an explanation of benefits (EoB) to families for their review, so that they can catch errors and help reduce Medicaid fraud.
- 4) Lock in prior authorizations for Medicaid prescriptions for a minimum of one year, or the life of the prescription, depending on need and prognosis. Every time a prescription is rejected, this requires both several entities access a problematic Xerox system. Some types of medications for people with IDD are not going to change, so by extending the length of time before re-authorization can reduce workload. This change will also help people rural areas who sometimes wait months for supplies to arrive, allow them to refill their prescriptions in a timely manner.
- 5) The Council strongly recommends increased use of telepractice for waiver recipients. Currently, SDS has a regulation that disallows billing Medicaid for waiver services provided via distance delivery. We suggest removing this clause so that some services, where appropriate, can be delivered more cost-effectively to our remote residents. Telepractice also saves money for our residents statewide, as it has been shown to be a cost-saving measure even in urban locations (American Telemedicine Association, 2015). To this effect, the Council wishes to applaud SDS's efforts to pilot a project that would provide ICAP re-assessments via distance delivery. We encourage the division to increase such assessments and re-assessments via telepractice to reduce costs.
- 6) Lastly, the Council hopes that through other cost saving measures and/or an improved financial position of the State of Alaska, SDS will be in a position to bring the annual draws from the waitlist back up to 200 per year.

The Governor's Council again wishes to thank SDS for opening the proposed DDDR draw reduction up for public comment. It is only with stakeholder input that we can make the most informed and best decisions for Alaskans with intellectual and developmental disabilities. The Governor's Council stands ready to help in any way that we can, to assure that DDDR annual draws are increased in the future.

Sincerely,



Jeanne Gerhart-Cyrus,
Developmental Disabilities Committee Chair



Dean Gates,
Medicaid ad hoc Committee Chair

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