



THE STATE
of **ALASKA**
GOVERNOR BILL WALKER

Department of
Health and Social Services

GOVERNOR'S COUNCIL ON DISABILITIES
& SPECIAL EDUCATION
Patrick Reinhart, Executive Director

3601 C Street, Suite 740
Anchorage, Alaska 99503-5924
Main: 907.269.8990
Toll Free: 1.888.269.8990
Fax: 907.269.8995

11-30-15

Re: Updated DDDR "waitlist" policies

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 DD Council, we work with Senior and Disabilities Services 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 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 wishes to recognize the work that Senior and Disabilities Services (SDS) has done to update the Developmental Disabilities Registration & Review (DDRR) policy. However, discerning these changes was difficult because the notice for public comment on these policies did not include a copy of the old policy nor the chart explaining the scoring system. Although we were able to obtain the needed documents directly from SDS staff, these missing items made it impossible for the general public to provide comment. Although the Council has made this request in several of our recent public comment letters to SDS, we once again implore the division to always include the old policies with the new, as well as a crosswalk detailing the changes, so that individuals with intellectual and developmental disabilities and their families can comment on the policies that greatly affect their lives.

That being said, the Council commends SDS on the updated policy for including more definitions and clearer roles and responsibilities for all parties involved in the DDDR process. We also appreciate the updated language from Mental Retardation to Intellectual Disability; however, this change also needs to be made to the application. Attachment A of the new policy, page 5, question 11 should read "intermediate care facility for Individuals with Intellectual Disabilities (ICF/IID)."

The Council has several other specific suggestions to the policy. Under "Responsibilities," on 1.b., please include mention of the release of information form if the applicant is not submitting their own application. On item 2, include the information that STAR coordinators are part of

a free service to aid in the application process. Under “Procedures,” include a third timeframe (item c) outlining expedited processes for individuals in crisis, similar to the process on page 4 of the old policy, which outlines the 6 situations that constitute crises for expedited review. Item 2.a. regarding the application should also include information on how individuals can obtain a paper copy of the application.

In the “Scoring and Selection” section, please include the explanation of scoring chart (attachment A of this letter). The explanation of scoring chart was not included in the e-Alert (it was obtained from Maureen Harwood on 11/4/15) but should also be made publicly available on the SDS website and include a narrative explaining in far more detail how the scoring procedure works. Since the application relies so heavily on the applicant’s self-scoring, there should be much more guidance to help the applicant arrive at a score that is as close as possible to the score an SDS Qualified Intellectual Disabilities Professional (QIDP) would assign. This will alleviate confusion and frustration when applicants receive their final scores, and reduce the number of inquiries and questions your office receives regarding scoring. Lastly, the narrative on the scoring explanation chart should also let applicants know that after being drawn for a waiver, only those individuals with one or more of the five qualifying diagnoses (intellectual disability, seizure disorder, autism, cerebral palsy, and “other intellectual disability”) are actually eligible for waiver services. Not all applicants know that the waiver is restricted to these five diagnoses, so the Council recommends making this clearer in all steps of the application process. Likewise, the Council requests greater explanation on the definition of “other intellectual disability” in SDS policies (i.e. IQ thresholds, etc).

The Council is concerned that the application no longer serves the needs of Alaskans with disabilities. Since the application is geared toward individuals in crisis, applicants who need waiver services for maintenance are given low scores, despite their high need. For example, there are no questions concerning the quality of life and how people spend their day without services. We also believe that it is difficult for applicants to communicate their need for services in these fourteen questions. These questions lack prompts for how applicants and family members should be answering these questions. STAR coordinators have figured out the scoring criterion over the years, but ambiguity remains for people who have not completed an application before. We have several suggestions to improve the application:

- On the top of the page, notify applicants that if they are drawn for a waiver, they will have to undergo an ICAP assessment, to determine level of care. Letting people know about this step earlier in the process can alleviate some misunderstandings about what it means to be on the DRR and to be drawn for a waiver.
- The application should also include narrative questions about the ability to perform daily tasks independently and unassisted for a clearer picture of an individual’s need and actual day-to-day functioning. This narrative would also allow for a description of hands-on care needed and/or behavioral and supervisory needs.
- Question 2 needs more description to distinguish it from #1, as these could very well be the same behaviors.

- Improve the “Community Participation Concerns” questions. Currently, the first 3 items are behavioral. What about those applicants with no behavior issues that require 24/7 supervision due to their inability to care for themselves, make their own decisions, or move themselves around?
- Clarify question 4 on victimization. What sorts of evidence would be appropriate?
- Question 5 favors those who should be on a CCHMC waiver. Consider revising so that able-bodied folks with IDD’s can be served.
- Service needs should include physical therapy, occupational therapy, and therapeutic massage.
- Questions 12-14 ask families to admit their failures in caring for the applicant, and there is fear that information could promote out-of-home placements. These fears may not be baseless; if a STAR coordinator is completing the application on behalf of a family, they are required as mandatory reporters to report neglect. Rewrite this question so that it more accurately addresses the amount of time and energy spent providing required care for the individual.
- Question 14 should elicit information about hands-on care and/or level of supervision required for safety.
- The paragraph on top of page 4 under “Service Needs” does not define the reason for these questions. It could state “This will help SDS plan/project service needs in the future,” or be marked as optional.
- The application could be improved by asking if the parent/caregiver is supporting more than one individual with a disability, or if the parent/caregiver experiences a disability themselves. This information indicates greater need for some applicants who are closer to crisis.

In addition to these suggested changes outlined above, the Council recommends restarting the DRR Ad Hoc Committee to review the application, policies, and scoring procedures every 2-3 years to assess that the form and processes remain efficient and suitable for the applicant’s needs. For example, the ad hoc committee may wish to create separate applications or waitlists for adults and children, or to reinstate the policy to award applicants points for length of time on the waitlist. Because of the dynamic nature of funding, quickly changing Medicaid reforms, and shifting needs in the state, these processes and the DRR application should be reviewed periodically to ensure they continue to appropriately address needs.

The Council appreciates the inclusion of attachment B on the DRR standardized criterion, but this document does not indicate how it is to be used. Is this for internal SDS use or is it also provided to applicants? If not, we suggest that SDS begin attaching this document to applications, or make the document public in some other way, for greater clarity during the application process.

Attachment C, the new sample letter with scoring information, deviates slightly from the old letter format, dated 2014 (obtained from Maureen Harwood on 11/4/15). First, the old letter format contained more information that is useful to applicants than the new format, such as

what a score of zero means, and what may influence a person's eligibility for services such as available funding, level of care requirements, and Medicaid eligibility. We recommend that language from paragraph 4 in the old letter be put back into the new letter template. Second, the letter should also include in paragraph 5 a recommendation that applicants apply for Medicaid now, if they have not already done so, as was stated in the old letter template. This could also include information about TEFRA, such as how children may be considered independent from their family income for eligibility purposes. Third, this letter should include both the applicant's self-score as well as the QIDP's final score. Last, the Council recommends including the attached brochure with the letter (Attachment B) to further illustrate all the steps in the waiver process. Lastly, all of these policies, attachments, and the scoring chart should be made publicly available on the SDS website.

The Council wishes to thank SDS for the opportunity to provide feedback on the DDDR policy changes. We are ready to assist in any way that we can, so that Alaskan individuals and their families receive timely access to Medicaid waiver services to achieve the best outcomes.

Sincerely,



Dean Gates, Chair
Medicaid ad hoc Committee



Jeanne Gerhardt-Cyrus, Chair
Developmental Disabilities Committee and
Council Workgroup on FASD

ATTACHMENT A

Explanation of Developmental Disabilities Registration & Review Scoring System			
Review of Life Concerns	Item Number	Score Multiplier*	Possible Points**
Community Participation Concerns			
	1	9	27
	2	7	21
	3	7	21
	4	8	24
	5	6	18
	6	7	21
Living Situation Concerns			
	7	11	33
	8	7	21
	9	7	21
	10	6	18
	11	9	27
Caregiver Concerns			
	12	10	30
	13	7	21
	14	5	15
Total Possible Score			318

*The score multiplier is the weight each question is given as determined by the Waitlist Ad Hoc Committee and Senior & Disabilities Services.

**Possible points is the highest number of points possible for a given question.

The points given for a question is determined by multiplying the level of need by the score multiplier:

- 1. = No need/Not Applicable 0
- 2. = Minor need 1
- 3. = Moderate need 2
- 4. = Major need 3
- No 0
- Yes 3

What is the I/DD Medicaid Waiver?

Similar to other 1915(c) Medicaid waivers, the I/DD Medicaid waiver, allows the State of Alaska to offer a choice between home and community-based services and institutional care for people who meet waiver service criteria.

The I/DD waiver specifically serves participants under the following 5 qualifying diagnoses:

- 1) Intellectual Disability
- 2) Other Intellectual Disability – Related Condition
- 3) Cerebral Palsy
- 4) Epilepsy
- 5) Autism

Possible services available for select persons on the I/DD Waiver include:

- respite care
- community inclusion supports
- residential supported-living
- nursing oversight
- care coordination
- and various other services

Intellectual and Developmental Disabilities (I/DD) Medicaid Waiver



Anchorage Office:

550 W 8th Ave
Anchorage, AK 99501

Tel: (907)-269-3666 **Fax:** (907) 269-3639

Toll Free: 1-800-478-9996

Fairbanks Office:

751 Old Richardson Highway, Suite 100-A
Fairbanks, AK 99701

Tel: (907) 451-5045 **Fax:** (907) 451-5046

Toll Free: 1-800-770-1672

Website:

<http://dhss.alaska.gov/dsds/Pages/dd/default.aspx>



Intellectual and Developmental Disabilities (I/DD)

VISION:

"Choice, safety, independence and dignity in home and community-based living."

Senior and Disabilities Services

I/DD Unit

I/DD Waiver Steps:

STEP 1: Developmental Disability Eligibility Application

Developmental disability (DD): a severe, chronic disability that: is attributable to a mental/physical impairment; is manifested before age 22; is likely to continue indefinitely; results in substantial functional limitations in three or more of the following areas of major life activity: self care; receptive and expressive language; learning; mobility; self direction; capacity for independent living; economic self-sufficiency.

Submit DD Eligibility application with appropriate signed supportive documentation to SDS.

Application Link:

<http://dhss.alaska.gov/dsds/Document/s/dd/DD-eligibility-application.pdf>

Application Instructions Link:

<http://dhss.alaska.gov/dsds/Document/s/dd/DD-eligibility-application-instructions.pdf>

*Note: A Short-Term Assistance Referral (STAR) representative can assist you with this application process free of charge. **Link to STAR Roster:** http://dhss.alaska.gov/dsds/Document/s/grantservices/PDFs/STAR_Roster.pdf

Await DD Eligibility determination from SDS.

If DD Eligibility is approved, you can proceed to Step #2.

STEP 2: Choice Options

A) Path Towards Grants: With a DD Eligibility Approval letter, you can pursue applicable DD grant opportunities to meet more immediate needs.

DD Grants Program Link:

<http://dhss.alaska.gov/dsds/Pages/grantservices/cddgp.aspx>

*Note: A Short-Term Assistance Referral (STAR) representative can assist you with this grants process free of charge.

Link to STAR Roster:

http://dhss.alaska.gov/dsds/Documents/grantservices/PDFs/STAR_Roster.pdf

B) Path Towards I/DD Waiver: Fill out and submit the Development Disabilities Registration and Review (DDRR).

DDRR Link:

<https://www.partners.hss.state.ak.us/dsd/s/ddwaitinglist/>

*Note: A Short-Term Assistance Referral (STAR) representative can assist you with this DDRR process free of charge.

Link to STAR Roster:

http://dhss.alaska.gov/dsds/Documents/grantservices/PDFs/STAR_Roster.pdf

SDS scores the DDRR to determine service score which puts the participant in the proper order (by need) on the I/DD Registry.

Note: the DDRR should be updated annually and can be updated at any time such as the participant's situation changing (i.e. address change, increased behaviors, loss of primary care giver, etc.).

Note: You can choose option A or B above, neither of the options, or both options A & B.

STEP 3: I/DD Waiver

When a participant is drawn from the I/DD Registry based on their DDRR service score, a certified letter will be mailed detailing the opportunity to pursue I/DD Waiver services. A Care Coordination Agency list will be enclosed, broken out by geographic region and waiver type served, from which to choose a care coordinator.

Care Coordination Agency List Link:

<http://dhss.alaska.gov/dsds/Documents/docs/services-providerlist.pdf>

Upon receiving this waiver selection letter, you can choose to decline services or pursue services.

If you choose to pursue I/DD waiver services, please complete the following in order:

A. Return self addressed stamped care coordination postcard to SDS denoting ***both*** the care coordination agency and individual care coordinator being chosen. * *Note: this postcard has a box to check and return to SDS if you are declining waiver services.*

B. Work with newly designated care coordinator to develop the initial level of care (LOC) packet. Submit this packet to SDS. If the LOC is approved and issued, proceed to C.

C. Work with the care coordinator to develop an initial plan of care (POC). Submit to SDS for determination.

Note: The LOC & POC processes are annual.