



Re: Developmental Disability Determinations Policy Changes

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 wishes to express both our commendations and concerns regarding the changes in the DD determination policies. We appreciate the change in language from "DD Program Specialist/Qualified Mental Retardation Professional" to "Qualified Intellectual Disabilities Professional (QIDP)" throughout the document. However, we suggest consistent use of person-first language wherever possible. For example, since QIDP seems to only include intellectual disabilities, this could be changed to "Qualified Intellectual Disabilities Professional (QIDP)/Qualified Developmental Disabilities Professional (QDDP)." Also, in the Policy section rephrasing "applicant is determined developmentally disabled" to "the applicant is determined to have a developmental disability" (page 1).

The Council recommends a slight wording change to the definition of "substantial functional limitation" on page 3 of the new policy. Please insert the word "chronologically" so it reads "...compared to the typical functioning of chronologically same aged peers." We applaud SDS for defining the roles of the applicant, the STAR coordinators, and the QIDP/QDDP roles (page 4) beyond the descriptions in the current policy. However, item 1.c seems to indicate that the applicant must complete the DDDR ("waitlist") application to register for home and community-based services. On this item, we would like to see the phrase "when available" replaced with "if the applicant so chooses." Item 1.d on this page should also more clearly indicate what "frequently, if necessary" means. Please include the language "For example, if service needs change or applicant requires a greater level of services."

The Council also believes that wherever STAR programs are mentioned, it needs to include Aging and Disability Resource Centers (ADRC), as the ADRCs are being combined with STAR programs in FY17. We also request the removal of the word "substantial" on item 3.b. The SDS QIDP/QDDP is responsible for determining whether an applicant experiences a developmental

disability based on substantial functional limitations; not whether they feel the developmental disability is substantial in nature. It seems as if the language of “substantial functional limitation” and “developmental disability” may have gotten conflated on 3.b., which is rectified by removing the word “substantial.”

We appreciate SDS’s efforts to standardize the timeframes with which these various processes should occur (page 4). We are pleased to see clarification of such timelines, but wonder if SDS could add the expedited timeframes for individuals in crisis. What is the expected turnaround time for individuals who cannot wait 35 days to receive their determinations, and therefore services?

We appreciate the increased explanation of re-determinations of eligibility (page 5). SDS has generally been re-evaluating applicants at 4 major life stages, and the new policy adequately explains that these occur at ages 4, 7, 16, and 18-22 years of age, rather than annually.

However, the new policy is significantly shorter and less specific than the current policy in place. The Council is concerned that a policy lacking clarity has more potential for subjectivity, interrater unreliability, and errors in determination. Whereas the current policy gives specific definitions for substantial functional limitations and considerations in each of the 7 life areas drawn from the Ohio Eligibility Determination Instrument (pages 5-9), the new policy is extremely limited and has omitted such explanations completely. The Council requests that significantly more description be given in each of the 7 life areas that more adequately explains what abilities are considered. If SDS no longer follows the Ohio instrument, then a new instrument should inform these descriptions and be cited in the new policy. We have a few suggestions to include in the expanded definitions (but not limited to):

Self-Care: This definition should take into consideration the need for prompts, reminders, and redirection, as these also limit independence and require supports. It should also consider a person’s chronological age in determining what self-care abilities are appropriate. This section should also include mention of personal hygiene, in addition to toileting. Lastly, please include a mention of safe and appropriate meal preparation for individuals under the age of 16.

Receptive and Expressive Language: The Council greatly appreciates the clarification of the “ability to understand and use social language” as this is an important consideration for our population that can limit functionality.

Learning: Learning needs to be demonstrated globally in this section. The ability to access cognitive ability in daily life consistently and dependably, including novel situations and when under stress, should also be considered, as this affects independent level of functioning. Learning should also include consideration of the fact that these diagnoses are often not medical conditions that can be fixed or improved. So in some cases, being able to complete day-to-day tasks associated with living a comfortable life does not require the ability to learn or demonstrate anything new. This definition should also state that IQ scores are not the sole factor in determining substantial limitations in learning.

Mobility: This section should also include mention of a person's ability to reliably and safely navigate the spaces around them without getting lost, forgetting where they are, or otherwise putting themselves in danger.

Self-Direction: The last 2 sentences on Attachment A relating to behavioral reluctance and refusal to perform tasks should be moved into the "Self-Direction" section above to improve clarity. This section could also recognize that reluctance or refusal may be a function of someone's inability to perform the task. The ability to perform a skill does not translate to ability to know when the skill needs to be performed, being able to initiate the skill, or adapting skills to various situations.

There should be a header separating the first 5 life areas from the remaining 2 life areas, indicating that capacity for independent living and economic self-sufficiency are only assessed for individuals aged 16 and older.

Capacity for Independent Living: Please include a consideration of a person's vulnerability to victimization. This section should also include mention of safe and appropriate meal preparation.

Economic Self-Sufficiency: Applies only to applicants aged 16 and over who are not enrolled in educational programs.

It seems as if use of the FEAST model (current policy, page 9) has been abandoned in the new policy, however, no new definition of reasonableness standard is provided. The one sentence definition of this term on page 3 is wholly insufficient for explaining how substantial functional limitations are determined. If FEAST is no longer being used, the Council requests another model or an expanded definition be presented for reasonableness standards. We would also like to see the addition of "TEFRA documents" and "Individual Family Support Plans" listed as examples of supplemental documents on attachment B and the application itself (Attachment C).

The Council requests further changes to the application. There are few instructions on the top of the document indicating that parents may complete these applications, not just STAR coordinators. The expanded instructions on the application should indicate that STAR coordinator services are free of charge and how someone is supposed to submit their application.

We are especially concerned that the narrative portions have been removed from the application. By eliminating the person's or family member's ability to describe their daily functioning, the application relies too heavily on medical documentation and diagnostic tests. The Centers for Medicare and Medicaid Services (CMS) is moving toward a more person-centered model, where narratives can richly describe the barriers that people with developmental disabilities face. We request that the narrative sections be returned to the new

application to both aid in making appropriate determinations and ensuring the application process is person-centered. We would also appreciate clarification on the application of what “health aide records” would be considered acceptable documentation and what “history documented in current records” would constitute.

Lastly, it appears that the current DD determinations policy is not publicly available online. The Council suggests that the new policy be made available on SDS’s website. In order for this policy to be effectively utilized by the public, much of the language will need to be amended. For example, the current readability of this document is at a Master’s degree reading level (18th grade). This policy needs significant wording changes and descriptions to be reduced to a 3rd – 5th grade reading level not only for the general public and applicants, but also for STAR coordinators, ADRC staff, and SDS QIDP/QDDP staff.

The Council appreciates SDS’s effort to further update the DD determinations policy. As the state DD Council, we thank you for the opportunity to provide comments on these proposed changes. We look forward to assisting SDS in any way that we can to help create a clear and accessible policy for determining developmental disabilities in Alaska.

Sincerely,



Amy Simpson,
Council Chair



Jeanne Gerhart-Cyrus,
DD Committee Chair