



THE STATE
of **ALASKA**
GOVERNOR BILL WALKER

Department of Health and Social Services

GOVERNOR'S COUNCIL ON DISABILITIES
& SPECIAL EDUCATION
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3/17/16

RE: Intellectual & Developmental Disabilities (IDD) Waiver Renewal Application

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 (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 DD Council is providing comments on proposed recommendations that may have an impact on individuals with intellectual and/or developmental disabilities and their families.

We are pleased with the opportunity to provide comment on SDS's upcoming Intellectual & Developmental Disabilities (IDD) Waiver renewal application. We are especially excited that SDS has not only begun to hold webinars that cover regulation changes and allow for questions and public comment, but they are also recorded and posted to YouTube and the SDS website. These measures greatly increase the accessibility of regulation changes to the general public. Although the IDD waiver application largely continues with current approved waiver processes, there are several new provisions in this application that the Council is concerned about, including the reduction in draws from the Developmental Disabilities Registration & Review (DDRR) "waitlist," new provisions for conflict-free care coordination, and the transition plan on settings.

Reduced draws from DDRR. As stated in a previously submitted comment letter (Appendix A of this letter, dated 2015, pgs. 6-9), the Council continues to be concerned about the reduction in draws of applicants from the waitlist to receive services. In reducing the number of applicants drawn from 200 per year to only 50 per year, we are certain that this change will adversely affect the quality and availability of services to Alaskans who experience IDs.

Notably, the Council feels that by not keeping up with the annual demand for waiver services, this change will result in:

1. increased length of time spent waiting for services, which has a trickle-down effect that results in people applying for the DRR much earlier;
2. incredible financial stress and caregiver burdens on families while they wait;
3. increased risk of interaction with the criminal justice system to the individual because they did not receive appropriate early services and supports; and
4. increased cost to the state in the long-run, as waitlist applicants are forced to use grants, state general funds, or seek costly out-of-state placements.

The Council requests that the annual draws be increased to 175 persons from the waitlist to receive services, in accordance with our recent request to the legislature (please see Appendix B of this letter, pgs. 10-11).

Conflict-free Care Coordination. Appendix C of the waiver renewal application covers participant services, including care coordination; however, the Council did not find the phrase “conflict-free” in reference to care coordination services in this section (pgs. 42-46). The Council requests further clarification of how care coordination services will be conflict-free in this section, as well as on pages 99-100 of the application. We have previously submitted several suggestions to SDS as to how to clarify these issues (letter dated 3-7-16, and provided in Appendix C of this letter, pgs. 12-14) which we also hope to see incorporated into the waiver renewal application.

Program Administrators. Each service section includes the following requirement that needs clarification, “A Program Administrator for a residential habilitation agency may not act as or be appointed as a Program Administrator for any other types of home and community-based waiver services. Notwithstanding this prohibition, a Program Administrator may be appointed to manage more than one service if appropriate to the service location and if on site management requirements of the service are met (pgs. 44, 46, 49, 53, 56, 59, 62, 71, 79, 88).” The Council seeks further clarification of what might constitute an “appropriate service location” and what type of “on site management requirements” would allow for such an exception. What will be the deciding factors? We wish to make sure that rural exceptions are only made if absolutely necessary, to protect families in cases of potential conflict.

Transition Plan on Settings Compliance. In addition to the aforementioned issues, the Council wishes to restate our various concerns regarding the latest version of the transition plan on settings (version 3) to comply with the March 2014 CMS final rule (pgs. 10-14 of waiver renewal application). Rather than enumerate them again here, we have attached our previously submitted comment letter as Appendix D (pgs. 15-19 of this letter), and hope that SDS incorporates our thoughts into both the transition plan as well as the waiver renewal

application.

Assessment Tools. The Council noticed that the Adults Living Independently (ALI) and Adults with Physical & Developmental Disabilities (APDD) waiver applications include use of a new Truncated Consumer Assessment Tool (TCAT) to reduce lengthy annual reassessments. The TCAT, or other shortened assessment tool, does not appear to have been added to the IDD waiver renewal application (pgs. 21-40). However, Appendix D (pgs. 101-102) references the “CAT and TCAT assessments,” which are not currently used for the IDD waiver and were not mentioned anywhere previously in the application as new tools. The Council suspects this is an error, and that language should be replaced with the “ICAP assessment.”

In fact, the Council requests that a shortened instrument be used for level of care (LOC) reassessments for the IDD waiver, too; that this tool be administered to recipients less frequently than annually; and that SDS consider administering this tool remotely (via teletechnology). Currently the ICAP is used for IDD waiver recipients every 1-3 years; however, by definition, individuals deemed to have an IDD are permanently disabled. Because they are permanently disabled, it makes constant reassessment of functionality inappropriate, unnecessary, and a waste of state resources, as we also stated in our 2015 comment letter on the waitlist reductions (Appendix A, pgs. 6-9). The Council wishes to reduce the burdensome stress on individuals and families who are regularly undergoing LOC reassessments for permanent disabilities. The Council is aware that SDS has been piloting a project to administer shortened ICAPs remotely, and we encourage SDS to include this new process into the waiver renewal application. We also believe that the Plan of Care (POC) form should be redesigned so it is less burdensome and lengthy for the participant to complete annually. Lastly, we also suggest a cost-saving measure that utilizes a shortened POC form for interim years, to be completed every 3-5 years.

Employment. Pre-employment was not delineated on page 41 in the summary table which lists the waiver services which are offered by SDS. The only mention in the waiver application of “pre-employment” is on page 67 under ii(C), stating an “ability to conduct pre-employment assessments” be a skill of the Supported Employment administrator. The Council requests that it be explicitly stated in the waiver application that pre-employment is included within supported employment. Pre-employment should be listed separately to best ensure the clarity of service options available is adequately explained. The Council also feels that the rate for pre-employment should be included on pages 173-181.

We also recommend a change to the term “sheltered workshops” on page 49. This should be changed to “supported employment,” so that it reads, “All day habilitation services must be

prior authorized and do not include vocational services such as supported employment." This language better reflects Alaska's commitment to ending sheltered workshops.

Quality Measures. Lastly, the Council joins the Alaska Association on Developmental Disabilities (AADD) and other organizations in our support for the adoption of National Core Indicators. Although Alaska has not yet joined the majority of other states who are currently collecting these data, we believe that such a move would greatly increase our ability to measure person-centered outcomes and quality of life. Not only do these National Core Indicators allow us to measure important aspects of life such as dignity and respect, but would also allow Alaska to compare our service delivery system to those of other states and to national averages.

The Council is pleased to see the inclusion of the new rate structure for care coordination included in the waiver renewal application. We appreciate the hard work that SDS has conducted to get conflict-free care coordination, the transition plan on settings, and the four waiver renewal applications completed, often with overlapping deadlines. These policy changes have required significant restructuring of the service delivery system in Alaska, changes that will only increase if the state decides to move forward with the 1915 i and k state plans for home and community-based services. As always, the Council remains available to assist in the creation or revision of policies and procedures as SDS moves forward with these many initiatives. Thank you for your time and the opportunity to comment on the IDD waiver renewal application.

Sincerely,



Dean Gates, Chair
Medicaid ad hoc Committee



Jeanne Gerhardt-Cyrus, Chair
Developmental Disabilities Committee &
FASD Workgroup

Appendix A: 2015 Council comment provided to SDS



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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 DRRR 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 DRRR annual draws are increased in the future.

Sincerely,



Jeanne Gerhart-Cyrus,
Developmental Disabilities Committee Chair



Dean Gates,
Medicaid ad hoc Committee Chair

Sources Cited

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- Loeber, Rolf & David Farrington (eds). 2001. *Child Delinquents: Development, Intervention, and Service Needs*. Sage: Thousand Oaks, CA.
- Magaña, Sandra, and Matthew J. Smith. 2006. Health Outcomes of Midlife and Older Latina and Black American Mothers of Children with Developmental Disabilities. *Mental Retardation* 44(3): 224-234.
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- Schweinhart, Lawrence J. 1993. Significant Benefits: The High/Scope Perry Preschool Study through Age 27. Monographs of the High/Scope Educational Research Foundation, No. 10. High/Scope Educational Research Foundation, Ypsilanti, MI.
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GOVERNOR'S COUNCIL ON DISABILITIES AND SPECIAL EDUCATION



Please join the Council in supporting an annual draw of 175 from the Developmental Disabilities Registration and Review DDDR (“Waitlist”)

WHAT IS IT?

The Developmental Disability Registration and Review (DDRR “waitlist”) is a program registry for qualified individuals with intellectual & developmental disabilities who meet “institutional level of care.” The registry provides an avenue for these individuals to receive the Medicaid waiver for Home and Community-Based Services when funds become available. The DDDR is managed through the Division of Seniors & Disabilities Services (SDS), and their plan is to reduce the DDDR waitlist annual draws from 200 consumers to 50 consumers per year as a way to save money in the short-term.

WHY IS THIS AN ISSUE?

- Because of the state’s commitment to draw 200 families from the DDDR for services since 2005, the number of families waiting for services has decreased from over 1200 to less than 700, currently. Reducing the draws by 75% will increase the number of consumers waiting for services and possibly triple the average wait time of 3 years.
- Families that are supporting individuals with developmental disabilities are much more likely to reduce work hours or leave the work force in order to care for their child.
- Research shows that waiver-funded supported employment services result in more job placements, higher wages, and work hours per week for individuals with disabilities. Employment ultimately has the potential to result in cost savings and better quality of life.*
- The average cost per I/DD waiver in-state is just under \$80,000 while the average cost for an out of state placement is over \$120,000.
 - Reducing the number of draws from the registry will increase pressure on state-funded grant dollars and, in some cases, result in higher-cost services if their child is placed in an out-of-state intermediate care facility.

ALTERNATIVE SAVINGS

The Council believes that we can accomplish the same level of projected savings from waiver services by implementing some of the strategies being explored now by SDS under the 1915i and 1915k state plan options beginning in 2017 as well as reviewing some current ideas, such as:

- **Streamlining the eligibility and level of care re-determination process.** Many people on the I/DD waiver have lifelong disabilities, such as Downs Syndrome, and their conditions are not going to materially improve over time. Currently, the process requires a full review and authorization every 3 years. We suggest review every 5 years and much greater use of low-cost tele-technology for reassessments vs. in-person reviews.
- **Considering implementing “soft caps” on services.** By exploring “soft caps” the division can reduce the number of hours for many services and then require justification of the need for more than a certain number of hours when needed.
- **Establishing voucher program for purchase of supplies and other personal care items.** Using a voucher card similar to the Alaska Quest card used for food stamps, allow families and/or providers to purchase some medical supplies from Walmart, Costco, or other low-cost alternatives to medical supply companies. This would also prevent continuous delivery, a common practice now, resulting in stockpiles of unneeded supplies.
- **Allowing for purchase of smart-home technology and services that reduce the need for direct staff support.** Other states and the V.A. have shown significant savings by allowing more smart-home technologies like tablets and smart phones to help a person live independently.
- **Considering a package of new services to persons who do not quite meet institutional level of care in the 1915i.** Some people and families (i.e. FASD, TBI, ADRD) need only a little bit of support, such as supervision and cuing, to help maintain community living:
 - Individuals with FASD alone cost the state nearly \$2 million over their lifetime**, through their use of the correctional system, medical treatment, residential care, and lost productivity.
 - Providing early intervention to these individuals often avoids much costlier state-funded services later in life.

Please encourage HSS/SDS to reinstate waiver draws to at least 175 individuals per year

Resources:

*Jean P. Hall, Noelle K. Kurth 2013. Employment as a Health Determinant for Working-age, Dually Eligible People with Disabilities.

<https://kuscholarworks.ku.edu/bitstream/handle/1808/11286/Hall%20Kurth%20Hunt%202013.pdf?sequence=1>

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3/7/16

RE: Proposed Changes to Regulations Regarding HCBS Waiver Provider Certification

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 (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 DD Council is providing comments on proposed recommendations that may have an impact on individuals with intellectual and/or developmental disabilities and their families.

The Council is pleased to see progress on bringing Alaska into compliance with the Centers for Medicare and Medicaid (CMS) final rule on conflict-free care coordination. These proposed regulation changes to provider certification are one of many steps in the right direction towards this large-scale effort. The Council would like to see further clarification regarding these proposed changes. We suggest that the phrase "in a non-urban geographic area" be inserted on page 2 into provision (j) so that it reads:

*(j) The department may grant an exception to a provider **in a non-urban geographic area** under (a) of this section....*

Likewise, provision (j) (2) should add this text to clarify that these agencies must be in non-urban locations as follows:

*(j) (2) an agency, certified as a provider of home and community-based waiver services in **a non-urban** geographic area, is willing ...*

We also suggest moving up the definition of a "non-urban geographic area" from within item (3) up to provision (j). This move will clarify what is, and what is not, an urban geographic area up front, before the other details are provided. These three aforementioned changes make clear that it is not just *any* provider in the state who could apply for an exception, as the current regulation seems to indicate, but only those located in rural areas approved by CMS for exclusion from conflict-free care coordination.

The Council is also unclear on whether care coordinators will continue to be certified statewide or if they will be restricted to providing services only in specific locations. If so, this regulation needs to more clearly state that statewide care coordinator certification will be changing to locality-based certification. Further, if this is the case, this regulation should also spell out the new rules for care coordinators; for example, can they certify in several locations? Will the state be monitoring that care coordinators are actually providing quality services in these locations? The Council is in full support of a move toward more localized services, wherever possible. We are concerned that statewide organizations may claim to provide services to some of our more remote regions, without the ability or intent to truly provide the local information of services and frequent face-to-face visits that our recipients need and desire.

The third point of clarification involves the intended implementation date for these proposed changes. The Council assumes this will be June 30, 2016, so that some measure of conflict-free care coordination is in place by the time CMS reviews your waiver renewal application. We suggest that an implementation date go out on all public notices and future communications regarding proposed regulation changes so that the public may be advised as to when they can expect such changes may take place.

Additionally, provision (k) delineates an evaluation period of three years; however, current provider certifications are done every two years. We suggest the provider certifications be done every three years to correspond to these proposed timelines of the exception evaluations. This will reduce multiple deadlines and confusion for providers as well as serve as a cost-saving measure, lengthening the recertification timeline from every 2 years to every 3 years. This will also allow SDS to use the most current provider information when making their determination on exceptions.

It is imperative that provision (k) clarify how and by whom in the department will determine when there is no longer a need for an exception, as stated in the last sentence. For example, would one independent care coordinator moving into a rural area be considered sufficient reason to revoke a conflicted agency's exception? What about two coordinators? Why or why not? Provision (k) needs to be significantly expanded to reduce ambiguity in determining exceptions.

The Council also agrees that the last sentence of (k) could be simplified to read:

*If the department determines there is no longer a need for an exception **[as determined by ...], the exception will expire.***

When an agency exception is revoked or expires, the proposed regulation should require the agency to submit a transition plan for how and when people will be moved from their agency to another care coordinator. The Council requests that such language be added to these regulations before they go into effect to protect the waiver recipients and provide detailed guidelines for how agencies and care coordinators are to proceed. Without such measures in this regulation, agencies will be left to determine transitions on their own, if at all. We fear the burden will fall to the recipient if explicit blueprints are not outlined in these regulations.

Lastly, the Council wishes for further clarification on the 4 items under provision (l), which is quite vaguely written. Items 3 and 4 should require both internal dispute processes as well as external dispute processes (involving the state). We strongly believe it is important for SDS to be immediately notified of disputes and resolutions within conflicted agencies, and to be ready to play a significant role in resolving such disputes, if they cannot be resolved internally. A process needs to be detailed in these regulations for such documentation, and timely submission, of internal and external dispute resolutions. This is an extremely important issue for the Council, as we fear that internal dispute/resolution processes may not be transparent, and could even be detrimental to the recipient and their family. Conflicted agencies will have a vested interest in resolving their issues internally but the Council believes the state needs to interject themselves into such processes to protect individuals. We request that SDS implement a process to frequently check in on conflicted agencies to be sure that quality services are being provided, that conflicts are being reported and handled appropriately, and that recipients are satisfied with their care coordination and other services.

Overall, we are pleased to see the state moving toward conflict-free care coordination. Independent care coordinators will allow for greater freedom and choice for the individual, as well as someone to advocate on behalf of the recipient. The Council is extremely pleased that SDS held a webinar, open to the general public, in which staff walked participants through the proposed changes. This session was recorded to capture public comment and questions. These are all excellent efforts toward greater inclusion of the general public and waiver recipients in the formation of policies and regulations that affect the lives of people with disabilities. As always, we thank SDS for the chance to provide input on proposed regulation changes to make our service delivery system conflict-free, increasing the quality of life for all Alaskans.

Sincerely,



Dean Gates, Chair
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3/8/16

RE: Alaska Medicaid Transition Plan on Settings – Version 3

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 (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 DD Council is providing comments on proposed recommendations that may have an impact on individuals with intellectual and/or developmental disabilities and their families.

The Council is pleased to see progress on the Alaska transition plan on home and community-based (HCB) settings. We are the only stakeholder agency that has provided comments on all previous versions of the transition plan, and as such we were thrilled to see most of our suggestions addressed in this third version. However, we have a few further concerns regarding this latest version, detailed below.

Accessibility to the General Public:

1. Tracking Changes. As previously stated in a recently submitted public comment letter (on conflict-free care coordination provider certification, dated 3-7-16), the Council is delighted that SDS has increased their outreach to the general public on regulation changes. Although we applaud SDS for holding a recorded webinar to walk the public through the latest version of the transition plan and take any questions and public comment, we believe this process would have been smoother if the version 3 document had visible "tracked changes." Version 2 of the transition plan clearly demarcated new text, edits, additions, and omissions using blue text,

underlining, and strikethroughs, which are all standard, accessible, and easily understood editing mark-ups. The current version 3 of the plan does not visually identify such changes, making it more difficult for waiver recipients to understand what is different about this latest version of the transition plan, which is already an extremely difficult document to digest. We suggest tracking changes in all future revised versions or, at a minimum, providing a separate “crosswalk” document that walks people through the new changes.

2. *Settings Transition Webpage.* On page 9 the Council is very pleased to see an expanded analysis of residential and non-residential settings, as was suggested in our previous two comment letters. We are also relieved to see the checklist was included in this version of the transition plan (appendix B, which was omitted from the version 2 plan that went out for public comment). However, page 11 is confusing for the public because it lists several items relevant to the Version 2 plan which are no longer easily accessible on the SDS website: it has been moved into the News Archives. The Council recommends that SDS create an entirely new page devoted to the transition on settings. Such a page would include all previous versions of the transition plan, a link to the Medicaid Final Rule, FAQ documents prepared by SDS, the provider self-assessment instrument, links to training webinars/PowerPoint presentations, and any other relevant information.

Clarify Language. The Council has further specific feedback that we wish to see incorporated into Version 3 before it is submitted to CMS. On page 7, the language “1915(c) waivers” is used when describing the purpose of the Interagency Settings Compliance Committee (ISCC). Because SDS is doing significant work towards transitioning to 1915(i) and (k) state plans that will cover many of our HBC services, we believe this language should be more generic to include such possible changes. If “1915(c) waivers” could be changed to “Home and Community-Based Services” throughout the document, this would mitigate potential future confusion.

Provider Self-Assessment. The Council is also pleased to see the expanded efforts to capture and validate provider information in the mandatory self-assessment survey (pages 12-15). However, we believe calling this a “survey” diminishes the importance of the self-assessment and implies that it is voluntary or a feedback tool. Referring to this tool as a “mandatory self-assessment” instead, connotes that providers are required to complete the instrument.

Classifying Settings Compliance. Council members agree that this self-assessment has excellent questions; however, we are a little unclear on the connection between provider responses and how SDS will be making compliance determinations based on those answers. Is there a scoring system that will be used to classify settings into the 4 categories as outlined on page 13? Page 19 of the transition plan states that a project will begin in July to amend regulations, based on federal settings requirements. As we stated in both of our previous comment letters on the transition plan versions, we strongly believe the state needs to clarify and define how compliance determinations on settings will be made as soon as possible. We were disappointed to find that SDS did not believe that the phrase, “the same degree of access as individuals not receiving Medicaid HCBS” needed to be defined when reviewing our past comments (as stated on page 25). We would like to restate that this definition does need to be stated in this third version of the transition plan before submission to CMS, and before the regulation project begins in July. As we also stated in our previous comment letters, some other states defined what it means to have the same degree of access as individuals not receiving Medicaid HCBS in their very first transition plan draft (i.e. Utah). That Alaska still does not have its decision-making system outlined is troubling for the Council because we are falling behind the work of other states.

Transitioning Recipients. We request that the transition plan include details about SDS’s relocation procedures when closure action is taken against a provider (pg. 18), since those procedures will be used to transition recipients from non-compliant settings. The current transition plan does not actually clarify any of its recipient relocation procedures.

Time Frames. This timeline includes a more substantial length of time for SDS to incorporate public comment into version 3 before it is submitted to CMS, a major prior issue for the Council in the past two plan versions. This timeline also indicates that initial remediation plans will be submitted to SDS by September 30, 2016 and that SDS will approve remediation plans in June of 2017 (pages 21-23). The Council is wondering why SDS expects a 9 month turn-around time for reviewing these plans.

Personal Freedoms. Personal freedoms are a very important topic for the Council, where parents and waiver recipients have told us that house rules limiting personal freedoms make them feel as though they are being treated like children. The Council is especially concerned with language on page 26 in response to our comment letter on version 2 of the plan. It is stated here that SDS is not in a position to affect assisted living home regulations regarding house rules to allow for personal freedoms; however, this is an absolute requirement of the final rule from CMS. The Council advises that SDS work with the

state offices that regulate licensing and facility regulations to be sure that Alaska is in compliance with this extremely important aspect of the final rule. It is stated elsewhere in the current plan that SDS will work closely with these offices to add settings assessments into their current site survey processes (pg. 17), so we ask that SDS leads the way to create changes to prohibit them from allowing house rules that restrict personal freedoms. It will be too cumbersome and discriminatory for residential facilities to implement personal freedoms only for those HCBS recipients while continuing to restrict the freedoms of their other residents. In the interest of inclusion and equality for all Alaskans with disabilities, we insist that state offices discontinue to allow house rules when licensing state and local assisted living homes. Truly inclusive residential settings, that have the same degree of access as individuals not receiving Medicaid HCBS, would not restrict the movements and personal freedoms of their residents. To this effect, the statutes [AS 47.33.060](#) on house rules and [AS 47.33.300](#) on residents rights will also need to be amended to comply with federal settings requirements. The Council would like to partner with SDS and other state licensing entities on outreach, education, and training for providers on inclusiveness, individual freedoms, and self-determination.

Employment. The Council was pleased to see plans for a new supported employment regulation on competitive and integrated settings (pg. 30). This is a great step towards integrating Alaska’s Employment First law into SDS regulation and the Council stands ready to assist with the regulation development process and gathering stakeholder feedback.

Collaborative Efforts:

1. ISCC. We would like to see the “Governor’s Council on Disabilities and Special Education” listed as a member organization in the ISCC (pg. 7). During the webinar on this plan, SDS staff indicated that the Governor’s Council would be representing waiver recipients and stakeholders, so we wish to see our agency specifically listed as a member organization of the ISCC.
2. Settings Compliance Monitoring. The transition plan states that the Governor’s Council will be trained to evaluate settings compliance and report issues of non-compliance through Central Intake for possible investigation or remediation with providers (pg. 18). However, the Council is not volunteering for such a role, nor are we allowed to accept such duties, as the DD Act prohibits us from being assigned duties by SDS, as the state DD agency ([SEC 124.c.5.K](#)). Please remove our agency from this list of partner agencies regarding ongoing monitoring. Instead, the

Council is well suited to offer assistance with outreach, training, and providing assistance to providers and families on compliance with the settings rule through partnerships with the Center for Human Development and the Disability Law Center.

3. Program Administrator Training. The Council noticed a correction that needs to be made on the bottom of page 21, where item “SDS develops Program Administrator training...” should have a date of “February 2016,” not “January 2016,” as Council staff were part of this webinar. We truly thank SDS for including us in their efforts to field-test the provider self-assessment training webinar. By strengthening our inter-agency collaborations, SDS is able to include stakeholder interests much earlier in the process.

The Council appreciates all of the work SDS has done to include the voice of the most vulnerable Alaskans. We truly appreciate the opportunities to both give comment and feedback on proposed regulations, and to provide input during the regulation formation process. As always, we will assist in any way that we can to improve the lives of Alaskans who experience intellectual and developmental disabilities.

Sincerely,



Dean Gates, Chair
Medicaid ad hoc Committee



Jeanne Gerhardt-Cyrus, Chair
Developmental Disabilities Committee &
FASD Workgroup