

To: Duane Mayes, Director, Senior and Disabilities Services

Cc: Maureen Harwood, Health Program Manager IV, Senior and Disabilities Services

From: Kara Thrasher-Livingston

RE: Plan to cut day habilitation in the HCBW

March 22, 2017

I am writing this as a mother of 2 sons who have autism and HCBW services, age 16 and 18. I am guardian of the 18 year old. They are my only children. They both have severe/profound autism and are functionally nonverbal. I am writing this also as the guardian and sister of my younger brother, age 50, who has intellectual/developmental disability and HCBW services. He also has severe developmental disability and is functionally nonverbal. Our mother and stepfather live in Anchorage and they are both 80 years old. My father is 80 and lives in South Carolina. They are not able to care for my kids or my brother. We have no other family in Alaska.

I am also an employee of Senior and Disabilities Services. I have worked in the field of intellectual and developmental disabilities services in Alaska since 1994.

This letter is from my perspective as a parent, guardian, and family member.

As a sibling I was the main caregiver for many years for my brother as we grew up together in our family home. Both our parents worked. As a parent I have arranged for or provided myself 24 hour qualified care for my sons, since Dec 14, 1998, the day my first son was born. I have also provided care for my brother, and both my children, during times his HCBW supports were not available to him.

My sons were on the waitlist for 9 years before receiving the HCBW. During that time I arranged for all qualified care outside of preschool and school. Fulltime day care for 2 kids all the way from age 6 weeks through 7th grade – which meant all day long in the summer and over school breaks, and after school. I also trained the staff at the different day care places how to work with my kids so they would be more accepting of them. We were turned away from many day cares due to autism. I viewed it as self paid early social skills intervention as it was the only truly community inclusive experience my kids had.

I am very concerned about the proposed restriction of day habilitation to 8 or 12 hours a week.

Often day habilitation is viewed by others (outside of families) as “extra”, “just babysitting”, “free babysitting”, or “getting more easy work hours”. This is an assumption that lies behind all the negative projections that we get about our family member(s). We get free things and we don’t deserve them, or appreciate them. We are guilty of something. We are jealous of others. We are or should be ashamed. Or, we are always angry and ignorant of the system. Well, families don’t choose to have a child who continues to need 24 hour qualified care all the way into adulthood and ongoing. We do not wish the life we have on others. This doesn’t mean we don’t love and value our kids and our lives as is. We greatly appreciate the specialized supports that we can rely on to help us care for our family member.

We need and have a right to live a life of dignity as our peers do, who do not have a disability. For this we need some help.

Day habilitation is NOT babysitting. It is a specific goal based service and having ENOUGH of it is key to young people with disability/autism as it is the number of chances they get to do it right in the actual setting (community place) is the only thing that will get results you want. People with disabilities and especially autism do not “transfer” skills well – in other words you can’t teach people how to be social in isolation and expect them to get it right when they actually get to the outside. (Just ask the infant learning people!)

If day habilitation has not been delivered correctly by providers, then re-education or a sanction process with clear regulation is needed. Families and individuals should not have to experience isolation, suffering and loss because of lack of oversight, clear direction and education to providers.

I realize that HCBW services are not “so the parent can work”.

I am a parent. I also have invested in an advanced degree with emphasis in disability services, and have 21 years in of service to the disabled community in Alaska. I did this because I am dedicated to serving my community in this capacity. I did this before I even had my kids. I did not plan to have children with severe autism. I am just doing the best I can with what I have, like anyone else. I am concerned that loss of vital supports to my kids that happen during the workday will cause me to be unable to work because I will need to provide care to my kids way past the ages that normal families provide 24 hour care to their kids.

What do other nondisabled young people who are 16 and 18 years old do when their parents are working? They maybe have a job, go to school or otherwise just come and go to their home or friends places pretty much on their own. Some are onto their own lives by then and not even living at home. Eventually they grow up and move away, go to college, meet someone, have your grandchildren, etc. This will not happen for my kids.

Kids and young adults who are age 16 and over without disabilities do not need anywhere near the level of supervision and teaching that my kids need. Therefore there are no community supports that they could access on their own. I can’t just provide them with a house key and say “let yourself in after school and play video games until I get home, do some chores and call me if you need to”. This is what other parents with average kids can do. They are not safe without qualified supervision. I can’t just lock them in a room with some food and a camping toilet so they can be home alone with nobody else around, and just hope for the best while I go to work to keep a roof over our heads and food on the table.

Obviously that is a threat to health and safety, not to mention contrary to human rights, every moment of their early intervention, special education, speech therapy, OT, and habilitative supports to date. It would also get me reported to OCS, APS, and much worse. Doesn’t it make you ask what the options are for families like ours? How will I provide a safe structured meaningful day, every day for my young-adult-aging children by myself without help , forever?

Alaska no longer has an institution for people with intellectual and developmental disabilities. No family wants to place their loved one in an institution. The cost is astronomical compared to family and community supports. Where will people go? What will families do without help?

Reducing day habilitation overall to 8 or 12 hours a week per person without regard to their circumstances is in my opinion **a violation of the Home and Community Based Waiver itself**. The HCBW is to provide necessary supports for people who meet level of care and are choosing living in the community. It will result in even more isolation for people with disabilities. It will cause loss of skills, more human suffering, and increased human rights violations as people are hidden away, far from access to the community, and deemed a burden to families.

It will also cause loss of jobs, not only for parents and other family members but workers who provide day habilitation, and other supports. It will further increase the loss of educated people to provide supports to the disabled/elder community on all levels, whether direct care or in the workforce or higher education.

As an unpaid main caregiver I currently experience loss of work days due to lack of waiver staff support. It makes you dependent on a "stranger's" schedule, health, and circumstances in order to go to work. Loss of work days that are not sick days for yourself and the fact that raising a child with a disability means you CAN'T go to work as many hours as others is further isolation, marginalization, progressive unaddressed caregiver health problems, and devaluing of women in the workforce in particular because main unpaid caregivers are disproportionately female.

I observe that cutting day habilitation will not save money.

Day habilitation is reimbursed at 10.71/15 min individual and 7.50/15 min group. That makes 42.84/hr individual and 30.00/hr group.

Alaska has now become an employment first state. People who are of age for employment can be approved for supported employment services. Young adults typically want to get a job. It will cost 48.48/hr for individual supported employment and 33.96/hr for group. Some or all of the time spent doing day habilitation could become supported employment time for my children and other families like ours.

In home services (someone to teach skills to a person in their own home) costs 42.64/hr. This is almost the same as day habilitation, but the service must happen at home, on a 1:1 basis only. My concern with seeing a probable rise in "in – home" services is that people will lose community engagement and become more isolated. This is hard for young adults who typically need to stay active and have community involvement. It also will not save any money.

I want to ask you to consider the value of supporting families who help their loved one(s).

I offer an example of the current reimbursement rate value of the services I provide to my young adult children for FREE – in other words if I was not around to provide them. I am not proposing to be paid for these. Only to consider the VALUE of what we provide and the worth of options that are more useful for family and unpaid caregivers. I am using the service “family home habilitation” as my first example. This service is living with a family (not your own family) but it’s the closest to what I provide.

HCBW service and rate	How many units?	cost per unit	Total I provide for FREE
Family hab child	365 (one year)	150.01 a day (age 17 and under)	54,735.65 (child age 16)
Family hab adult	365 (one year)	119.93 a day (age 18 and older)	43,774.45 (child age 18)
			98,510.10 total I saved the State from paying for care, residential only!

This table represents the minimum that would be paid to others to care for my children (residential care) should I need to place them in assisted living home due to lack of services to help them live at my home. The 16 year old would have to get family habilitation child. The 18 year old would likely go to a group home. In time they would both be 18 and the cost would increase to group home times 2 per year – up to \$231,307.80 using today’s rate.

HCBW service and rate	How many units?	cost per unit	Total I provide for FREE
Family hab child	365 (one year)	150.01 a day (age 17 and under)	54,735.65 (child age 16)
Group home	365 (one year)	316.86 a day	115,653.90 (child age 18)
			Total cost to the State without my residential care: 170,389.55

Please note that in December of 2016 I provided my brother with 3 days of care in my home – 24 hour care – because his group home staff were all out sick and the home could not operate those days. As his guardian I must provide or arrange for a safe least restrictive place to live. I saved reimbursing a provider about 950.00.

As you can see families who are caring for their loved ones at home provide the bulk of services for FREE. What is being done to help those who are already helping their loved ones? If HCBW supports are considered as part of a holistic plan for a whole life – why are we not explicitly helping those who are already helping?

Rather than cutting day habilitation to 8-12 hours a week based on an overall average, I propose:

- Take more detailed data than a generic “average” of day habilitation.
- Determine utilization overall per age, location, and other waiver services.
- Develop projection of day habilitation alternatives based on actual utilization.
- Consider limiting day habilitation for people with the IDD waiver who have 24 hour out of home residential service (group home, family habilitation) due to obligation of those supports to provide community social activities.
- Consider eliminating day habilitation for people living in group homes.
- Consider making “Adult Day Service” available to the IDD waiver at 18 year and up.
 - According to Adult Day COPS there must still be goals of Adult Day plan
 - Service costs 84.11 for 4 hours and 21.00/hr for each hour after that up to 10 hours a day. (Many day habilitation requests for IDD adults are at 4 hours/day.) 4 hours of day habilitation costs 120.00.
 - Max cost 210.00 for 10 hours (vs 300.00 for 10 hours of group day hab max equivalent)
 - Allow max amount (10 hrs) Adult Day only when person with IDD waiver is living with unpaid main caregiver, relative to other supports including those of main caregiver
- Make Adult Day Services available to IDD/CCMC waiver only when the individual is 18 plus and lives with main unpaid caregiver
- Make certification as provider of “Adult Day Services” available to providers who are already certified in setting-based group day habilitation.
- Generally allow IDD waiver recipients to choose a blend of day habilitation and adult day services for centers with dual certification.
- Allow IDD recipients to receive limited 12 hrs/week Adult Day Services if they have group home or family habilitation (out of home residential).
- No limit on day habilitation for school age children up to age 21 living with an unpaid caregiver—depending on evaluation of other supports in their life such as school day and ESY. Limit to enough day habilitation for after school, winter and summer breaks.
- No limit on day habilitation for IDD recipients age 21 and up living with primary unpaid provider, subject to evaluation of other supports regardless of funding source. Unpaid provider supports must be a part of the 24 hour daily support to the person.
- No limit on respite service for primary unpaid caregiver for IDD ages 12 and up. Respite is reimbursed at the LOWEST amount of all waiver services and it helps the primary unpaid caregiver continue to give care. (This may generally reduce requests for day habilitation or prevent or delay escalation to other more costly services such as the out of home residential.)
- Keep disallowing all other services reimbursed during daily respite days.
- Develop mandatory training for day habilitation providers for quality and skill building requirements.
- Develop regulation language that spells out the requirements for day habilitation outcome.

Thank you,

Kara Thrasher-Livingston