

HSS-FSC Testimony

Jim Beck

Executive Director

Access Alaska, Inc.

September 6, 2013

Thanks for the opportunity to speak to you and for your interest in Senior and Disability Services (SDS) - the level of detail and depth of questions from the members is truly impressive and I appreciate the chance to listen in on your deliberations. Truly, the task before you all is enormous.

My colleague (Doug Toelle, Access Alaska's Fairbanks-based Advocacy Director) and I were preparing a data-centered presentation based on facts and figures and the piles of long-term care and Medicaid studies like the

- 2006 PCG Long-term Care and Cost Study,
- 2006 Lewin Group Medicaid 20-year Enrollment and Spending projection,
- ISER's 2006 Healthcare Cost Study,
- the Pacific Health Policy Group's 2007 Medicaid Program Review,
- HCBS Strategies' 2008 LTC Plan Recommendations
- and more recent studies like the ANTHC Medicaid expansion study and the Agnew::Beck long-term care study.

But clearly there is no shortage of numbers, data and analysis to guide your admittedly very difficult work. Not to mention a talented administration.

So instead of data...

I want to take you back to 1980. In Anchorage a group of parents were meeting and dreaming of a better life for their kids, who had very significant disabilities.

These parents knew their sons (this happened to be young men) were doomed to live out their lives in their parents' basements or in the nursing home (Nakoya) in which many of them already lived.

Keep in mind at this time there was no Americans with Disabilities Act (ADA), very few services, no accessible transportation, etc.

The parents eventually organized and founded a nonprofit organization and approached the legislature which funded a demonstration project. They used the funding to show that with the proper family and community supports, people with significant disabilities were able to live independently.

They set up Alaska's first Personal Care Assistant (PCA) program, they purchased accessible vans and started a small transportation program and they hired people - many with disabilities themselves - to help coordinate it all. This was all operated by one nonprofit organization - Independent Options Now.

This allowed Alaskan people with disabilities (PWDs), for the first time, to dream of a life beyond the nursing home. This began the journey of closing our institution at Harborview and our statewide concerted effort at building a long-term care system that favors home and community based services (HCBS) over institutions.

This was big stuff! These nine young men were now living independently in the community!

But:

- There was no Medicaid PCA option in the state; if you weren't one of the 9 guys in Anchorage you were out of luck...
- Those same advocates plus many new collaborators undertook a new effort - to bring the Medicaid PCA option to Alaska. They worked on this throughout the early 80s and finally in 1986 accomplished their goal, and the possibility of statewide PCA services became a reality when the legislature approved the addition of PCA services to the state's Medicaid state plan.

The PCA program went through many iterations over the years but one dream remained in the disability community - to have a PCA program that allowed the person receiving the care to hire and train their own PCAs and therefore exert control and choice in the way they lived their lives. Our dream was that the people receiving the care would direct how the care happened, who provided it, etc. This is the concept of consumer control and for many it means liberation.

We fought for this for years. It finally took an act of Congress, when the honorable Sen. Ted Stevens provided earmark funding to help Alaska rewrite its PCA program regulations and so the Consumer Directed PCA program was born in 2002.

For those of us who rely on this type of care this was one of the biggest wins in decades. These services often deal with people's most intimate needs. Who among us would NOT want maximum choice and control over who dresses us or how we are bathed? Personal care services are the foundation and cornerstone in the lives of many elders and people with disabilities, allowing us to work, to live in the community and participate in the Alaskan dream.

As Ed Roberts, the great American and father of the Independent Living movement said - "I could make choices and that is freedom."

It turns out the move was prescient, as the PCA program is and will remain one of Alaska's bulwarks against the rising cost of care that all states bear, but felt even more by Alaska, given our rapidly rising senior population (the fastest growing in the nation!).

These home and community-based services (HCBS) will play an increasingly vital role in Alaska's ability to plan for and respond to the state's incoming "silver tsunami."

Why?

- Average annual cost of PCA per person has not increased appreciably for 10 years (\$21,320 (Burnham, 2004), \$23,811 (Mayes, 2013)), while regulatory and administrative burden has increased dramatically in the same time
- Meanwhile, greater numbers of seniors and PWD are being served in this climate, providing massive value to the State of Alaska and her citizens.
- Keep in mind that Skilled Nursing Facilities (SNF) services are a mandatory Medicaid service - we all pay for every one of those beds, in some cases whether they are full or empty.
- Director Mayes' data yesterday showed that from FY09 - FY12, SNF average annual costs rose 29% while HCBS costs rose a mere 9% NINE PERCENT! in the same period.
- HCBS services happen in the community, where people live. They are scalable, and they are far less capital intensive than institutional services.
- Remember, people on Medicaid waivers are effectively being diverted from more expensive nursing home care, again providing measurable savings to the state.

It is important to remember that Alaska's LTSS system is one of the best in the nation. We are consistently ranked in the top 5 nationally for balanced spending between HCBS and institutional care. This is paying measurable dividends in slowing the growth of Medicaid spending, and will continue to do so as long as the HCBS systems and services are kept strong by the legislature, the Department and of course the providers.

As Mr. Mayes pointed out in his presentation yesterday, we must do everything in our power to keep the least costly, community-based end of our continuum of care as strong as possible. It is the ONLY way we as a state will thrive through the coming decades of growth. We all stand on the shoulders of the giants who came before and bear a moral duty to honor their work by continuing to invest in a quality system of care for Alaska's elders and people with disabilities. Mr. Chairman I greatly appreciate your committee's commitment toward that end and stand ready to assist you all in any way possible.