## Testimony to House Finance Committee September 6, 2023

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My name is Sioux Douglas, I'm a 36 year resident of Juneau, and I thank you very much for this opportunity to speak before you. Please note the hard-copy of this testimony that has been provided to you.

Before I proceed with my testimony I'd like to say that I recently learned that you are meeting one week a month to better understand the DHSS budget, which we know is a huge portion of the entire State budget, and contains many complex details. Your special attention to this Department gives me hope that our testimony may be useful as you deliberate over the consequences of funding decisions. I understand that yours is the first Finance Committee willing to put in this kind of time prior to an upcoming session and I want you to know it's deeply appreciated.

I am the co-parent of a 45-year-old man who is developmentally and physically disabled. Jeff is totally deaf, cannot speak verbally, is autistic with some mental retardation, and has cerebral palsy. In spite of all this, he's mobile and capable of many things, but he cannot, by any means, live independently. Jeff lives in a wonderful group home in Juneau operated by *Symphony Homes and Services*. He is relatively healthy and will live longer than his father and I will. We are in our 70's, and I'm sure you can appreciate how important it is to us that Jeff is well-cared for now, as well as when we are no longer alive.

Sarah Bettridge, owner of *Symphony Home and Services*, will speak to you following my remarks, adding her deep concerns about the financial impacts of Medicaid Waiver regulation changes that were put into effect July 1 by the Department of Health and Social Services' Division of Senior and Disability Services. Last year, we knew that the Department was working on regulation changes, but we were caught off-guard with less than thirty days' notice that those <u>draft regulations with new additional changes from previous versions</u> would suddenly become effective so soon. We've been grappling with the effects to many consumers and to group home operators in Alaska in an atmosphere that is rushed, charged and challenging. Nevertheless, we have poured over the regulation changes, made numerous inquiries of the Department and from fellow

group home operators in Alaska regarding the impacts. As a result, we have distilled our work into 3 specific requests for you to consider.

In order to prevent closure of small group homes and the institutionalization of our disabled, we respectfully recommend and request that the House Finance Committee:

- 1. Fund portions of the FY15 DHSS budget that we describe in our testimony at the FY13 level because the Department's efforts to control costs by these regulation changes have unintended consequences: they actually move disabled Alaskans toward more expensive housing and care. Please fund day habilitation services for group home residents back to FY13 funding levels for the next full fiscal year to allow time for all of us to take a step back and implement truly sustainable visions and budgets for long-term service and support.
- 2. Direct DHSS to encourage and award small business owners who are innovative in cutting costs by creating financial incentives for those group home operators who are finding ways to reduce staff turnover (which is a major problem) and deliver quality care, at often one quarter to one half the cost of skilled nursing facilities by taking high need clients into their group homes.
- 3. We recommend that regulations and reimbursements for Care Coordinators be re-examined to prevent losing these experts who are such a valuable part of the Medicaid Waiver system.

Sarah's testimony will provide you the details to support the reasoning for these requests.

There is no question that our son Jeff's current physical and emotional good health will absolutely decline if his care and activities are reduced because of well-intended cost savings. But, please be aware that while we are describing Jeff and his very disabled housemate as examples, we are talking about the impacts to many group home providers and their residents all across the state. Our situation is not singular by any means. Another important consideration is that we are unusually hands-on parent- guardians, communicating and meeting often and

consistently with Jeff's home care providers. That is not the typical case throughout the state—as the Department will attest to. Too many of our developmentally disabled who live in group homes are totally dependent upon their Care Coordinators and the group home operators who care for them. Many don't have family, or if they do, the family is dysfunctional or so otherwise burdened with other responsibilities that they have left the care of their loved one pretty much to others, including the State of Alaska. One of our serious concerns is that if regulation changes cause deep reimbursement reductions to the providers, some of those assisted living group homes will have to close. Those providers simply won't be able to afford to operate any longer.

Jeff and his housemate are the fortunate recipients of financial support through what is now called the "Intellectual and Developmental Disabilities" (IDD) Medicaid Waiver program. Some of the regulations we are concerned about drastically reduce their weekly day habilitation hours in this program as an apparent effort by the Department to reduce the cost of the Medicaid Waiver services. I want you to know that I understand the challenges the Department faces when trying to contain costs. We respect how challenging it is to constrain costs now in anticipation of future growth and needs, but we are concerned about the impact some of the current regulations will have on the 2100 state-licensed assisted living facilities now, as well as in the future, and their ability to provide appropriate levels of care.

I read with interest just last week that Governor Parnell has called for regulatory reviews to lower costs to State government in all departments, not just within the Department of Health and Social Services. The legislature has a tough job figuring out where they might put monies back into the budget to off-set some of the losses the citizens of the State of Alaska will suffer. I also understand fairly well the responsibility and challenges you have as House Finance Committee members. I have worked for both the legislature and as a Division Director in the executive branch so know it is difficult to reduce costs while still serving your constituency as elected officials, as well as for the Department, as civil servants to the people of Alaska. My point is that Sarah and I are not here to cast dispersions. As trite as it sounds, we want to work with you and the Department in any way possible. We know this isn't easy and we hope our remarks and suggestions will be educational and useful. Please just keep in mind that reduced funding has the consequences of closing small group homes thus reversing the State's very

deliberate move away from institutionalization of the disabled. None of us want to see the DHSS budget grow in an unprecedented way and also create inferior care for our vulnerable population that deserves better.

This concludes my remarks, and again, thank you for the opportunity. Sarah is prepared to speak next and we will do our best to answer questions when she is finished.