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House Appropriations – Human Resources Division
Senate Bill 2012 – March 16, 2023
Testimony of Veronica Zietz, P&A Executive Director

Greetings Chairman Nelson and members of the House Appropriations – Human Resources Division. My name is Veronica Zietz and I'm the Executive Director of the North Dakota Protection and Advocacy Project (P&A). P&A protects the human, civil and legal rights of individuals with disabilities; this includes individuals with intellectual and developmental disabilities, mental health disabilities, brain injuries, and other impairments.

P&A was created in response to the deplorable treatment of people with disabilities in institutional settings. This resulted in US Congress passing the Developmental Disabilities Assistance and Bill of Rights Act of 1975, which recognized that a federally directed system of legal advocacy was necessary to ensure the humane care, treatment, habilitation, and protection of individuals with disabilities. Every US state and territory is federally mandated to have a protection and advocacy agency.

The population P&A serves is touched by almost every aspect of the Department of Health and Human Services Budget primarily Medicaid, Developmental Disabilities, Life Skills Transition Center (LSTC), Human Service Centers, the State Hospital, and Vocational Rehabilitation, though other sections also affect individuals with disabilities.

Chairman Nelson, last week you asked about implications of the Olmstead decision in relation to the State's services, specifically regarding census at state-run institutions. Anytime individuals with disabilities are unnecessarily placed in institutions, when they can be served in the community there is potential for an Olmstead issue. For this reason, it is in the State's best interest to focus on the development of home and community-based services (HCBS) and to ensure that's where financial resources are focused.

While P&A appreciates the services provided by the Department of Health & Human Services (HHS) there are challenges and concerns within the service system.

The home and community-based service system for individuals with disabilities is currently facing many challenges. P&A is seeing major problems around individuals with disabilities being discharged from services either through formal 30-day discharge notices, or an unwillingness to allow the individual to return if hospitalized or in another temporary placement. When this occurs, other providers are often unwilling to accept an individual into their services, which may result in individuals being funneled into institutional settings. Reasons provided for discharges include 1) workforce shortage and 2) lack of adequate compensation and expertise to serve individuals with complex needs.

I won't belabor the issue of workforce, as advocates and legislators, alike have spent much of this session discussing these challenges. I will, however, note that there are compensation disparities based on setting for individuals providing direct care to individuals with disabilities and other vulnerable populations. It is also worth noting that staffing shortages deter quality care for individuals with disabilities. P&A sees this every day as we receive and investigate a growing number of abuse, neglect, and exploitation reports.

Instead, I'd like to focus on the second point which I believe may be remedied by changes in policy/practice and refocusing state resources. The 30-day discharge process is outlined in administrative code and gives HHS the power to accept or deny a 30-day notice. In our experience a 30-day notice is generally accepted by HHS. In comparison to the discharge process for long term care (LTC) the process for individuals with disabilities is flawed in that it doesn't require the provider to secure a placement for the individual being discharged.

When individuals are given a 30-day notice HHS follows a process for requesting providers to review a referral in that area/statewide relative to their ability to serve the person being discharged. Many providers are not willing to accept new individuals due to being short staffed and lack of willingness to serve complex individuals. When a placement is not secured individuals end up in restrictive and expensive institutional settings, that our state has identified as the safety net (LSTC and State Hospital).

P&A works on these cases under our community inclusion priority. While P&A's client management database doesn't allow searching by "30-day notice" I was able to work with a handful of staff to provide you with some case examples that we are actively working right now.

P&A Case Examples:

- A 30-day had been given multiple times over the course of a couple years, but no other agencies accepted the client. The client stayed with the provider until the person was admitted to the

State Hospital. After the admission, the agency was unwilling to allow the individual to return to services and then discharged the client. There still have been no providers that have accepted this client and the client has been at the State Hospital since October 2022.

- The client was in the LSTC and transitioned to community provider. After experiencing some behavioral support challenges, the community provider discharged client to the State Hospital, where she currently remains.
- The client received a 30-day notice from two community providers due to behavioral challenges. Neither provider was willing to complete an outlier because of the challenges with obtaining them. The client was admitted to the State Hospital in August 2022 and remains there at this time.
- The client engaged in physical aggression which resulted in an injury to a staff member. Client went to the psychiatric unit and was then transferred to the LSTC.
- The client was living at home and getting in-home supports through community provider. Staffing was challenging and he was only getting 200 hours, the client was discharged from community services and went to the LSTC.
- The client was sent to State Hospital because of behavior (elopement). Once at NDSH client was discharged from provider services.
- The client's behavior (danger to self and others) resulted in admission to psychiatric unit at which point provider discharged.
- The client's behaviors/mental health needs (elopement and destroying property) resulted in discharge.
- Provider staff was unwilling to work with client due to behaviors (stealing and aggression towards objects/staff).
- Provider cited not having enough staff as the reason for discharge.
- Provider discharged because client's behaviors are too intense, and staffing is a concern.
- Provider stated staffing shortages is the reason for discharge.
- The provider is discharging because of staffing and inability to meet client's healthcare needs.
- Provider discharge is because the client's behaviors are becoming more challenging.
- Provider discharged because they don't have the mental health expertise needed to support client.

Each one of these anecdotes represents a real person who at some point in time was successfully served in the community and is now being served in an institutional setting at daily rate of $1,231.49/day or $449,494/year for each person at the LSTC (per Heather Jenkins Oct. 2022) and $1,223/day or

$446,395/year for each person at the State Hospital (average cost of care per bed across all units per Dr. Yabut testimony Feb. 2, 2023). This shows that our system is flawed, and the State must take action. Through our work, we have identified the following to be contributing factors for discharge from community-based services and subsequent institutionalization:

1. Flawed administrative code relating to discharge process.
2. Staffing shortages.
3. Inadequate level of hours/services determined by State versus person's actual needs (SIS assessment and outlier process).
4. Lack of adequate compensation to serve individuals with complex needs.

These problems within the service system are evident from LSTC's recent testimony which noted the facility didn't meet identified census goals for 2021 – 2023. This resulted in outspending their budget by $16 million. It is even more concerning that LSTC is not setting census goals for this biennium and is asking for an additional $16 million dollars for next biennium to address the increased population. Without reduction goals for State institutions, North Dakota will continue to push individuals towards institutional settings to the detriment of individuals with disabilities and at a great financial cost to the State.

The 67th Legislative Assembly through legislative intent included in HB 1012 Section 55 directed the HHS to seek an appropriation via the American Rescue Plan Act during the Special Session for the purpose of transitioning individuals from the LSTC to community providers. This language derived from the First Engrossment with Senate Amendments Section 16 which included one-time funding $5.2 million to be used for LSTC transitions to the community. Unfortunately when this topic was brought forth during the 2021 Special Session it was not selected for funding as HHS noted their Section 9817 Medicaid Plan held $4.75 million for LSTC transitions, $6.6 million for new services, and $4.4 million for HCBS infrastructure. Sadly, this investment which according to the 9817 document was to be completed in March 2022 did not result in the outcomes that were hoped for in relation to ensuring the transition of individuals to community settings. With this background in mind, I would like to share with you a variety of possible solutions.

Solutions:

1. Direct HHS to examine administrative code language and implementation regarding discharge to ensure individuals aren't left without services.

2. Study the payment disparities for professionals based on setting (nursing homes, basic care, assisted living, intermediate care facilities (ICF), LSTC, State Hospital, etc.) and create an equal playing field through targeted equity or equal distribution of inflators.
3. Include census reduction and average length of stay goals for LSTC in SB 2012.
4. Shift the LSTC's 23 – 25 biennium increase request from LSTC to HCBS providers, creating a $16M fund for direct payments to HCBS providers serving high need individuals with a zero-reject model in mind.
5. Direct HHS to examine the SIS assessment and outlier process and create reasonable method for request and appeal. Also include mechanism that examines cost-benefit of approving the outlier request over providing service in institution.
6. Reconvene the Transition to the Community Task Force with the intent to engage in active steps to achieve transition to community settings with target goals and outcomes.
7. Create a reimbursement mechanism for community providers to add the necessary support services such as behavioral support, occupational therapy, speech therapy, physical therapy, psychiatric support to ensure that a robust infrastructure in community services matches the services provided within institutional settings.
8. Create a process for community providers to request technical assistance/support from HHS when an individual is at risk of discharge. Whereby HHS staff/experts can provide HCBS provider with training, consultation, etc. to mitigate likelihood of discharge.
9. Create a public-facing online dashboard that tracks information on services provided to people with disabilities (intellectual, developmental, mental health, brain injury, etc.) that ensures the integrity of data provided. This should include the 1) number of people approved for services, 2) number of hours/services approved versus utilization, and 3) waitlist by service type or provider. This will assist in identifying gaps so targeted solutions can be proposed.

I would like to thank the Committee for listening to my comments and taking them into consideration as you begin making decisions on SB 2012.

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