THE NORTH DAKOTA OLMSTEAD COMMISSION
MEETING MINUTES OF
APRIL 20, 2022
NORTH DAKOTA HERITAGE CENTER AND VIRTUAL VIA TEAMS

MEMBERS PRESENT: Wally Goulet, Ryan Norrell, Siobhan Deppa, Honorable Bruce Romanick, Carlotta McCleary, Veronica Zietz, Representative Alisa Mitskog, Scott Burlingame, and Julie Horntvedt

MEMBERS ABSENT: Senator Judy Lee

OTHERS PRESENT: Dan Gulya and Carrie Berland of Protection and Advocacy, Kristen Dvorak from Autism Spectrum Disorder Advocacy Coalition, Jessica Thomasson, Tina Bay, Heather Jenkins and Dr. Paul Kolstoe from DHS, Carrie Varner with the DD Council, Donene Feist with Family Voices of ND, Jeannie Krull with ND Assistive, and Trevor Vannett from the DD Council

Co-Chair Goulet called the meeting to order at 1:03 p.m.

The agenda was approved as typed.

APPROVAL OF THE JANUARY 19, 2022, MEETING MINUTES:
A motion was made by Ms. McCleary and seconded by Judge Romanick that the January 19, 2022, meeting minutes be approved as typed. The motion passed.

MEMBERSHIP CHANGES:
Welcome to Co-Chair Ryan Norrell. Ryan Norrell is the new General Council for the Governor of North Dakota. Ryan was General Council with the State Water Board and the Public Service Commission and spent the last 7 years at Credit Services of Mandan. He stated that he has no personal experience with Olmstead but is wanting to learn and grow.

STRATEGIC PLANNING:
At the last Commission Meeting, Dan Gulya, Veronica Zietz, Wally Goulet and Scott Burlingame were assigned to a Strategic Planning Team. They have since come up with various materials.

Purpose Statement for the Olmstead Commission:

1. Provide Education
2. Create Awareness
3. Maintain a public presence
4. Collect and analyze public input, and incorporate it into work of the Olmstead Commission
5. Receive and respond to directed inquiries
6. Conduct research into Olmstead Commission issues such as service inequalities and barriers to integration

7. Promote inclusion and participation of person with lived experience in creation of policies and services that impact them

Mr. Burlingame stated that the most important thing that the committee did was narrow down what we do, so we can push forward the purpose of the Olmstead Commission. Ms. Zietz explained we covered all our bases to make sure that the Olmstead Commission has impact, and we have an outline for our work. Mr. Goulet said the purpose statement will help the public understand the Olmstead Commission. Ms. McCleary agreed the seventh item in the purpose statement is very beneficial.

MOTION:
A motion was made by Ms. McCleary and seconded by Ms. Deppa to adopt the Purpose Statement as presented to the Olmstead Commission. The motion was approved.

AUTISM SPECTRUM DISORDER AND LSTC ADMISSIONS:
Kirsten Dvorak with Autism Spectrum Disorder (ASD) Advocacy Coalition and the Arc was asked to provide an overview of the ASD Advocacy Coalition's concerns regarding the admission of adults with ASD at the Life Skills Transition Center. Ms. Dvorak explained the Coalition is concerned about the large population with a diagnosis of Autism that are living at the LSTC. The coalition wants to know what is the root cause and what is happening before the placement?

Ms. Dvorak stated that there are three ranges of ASD. High range: need support, usually non-verbal, behavioral problems. Mid-range: verbal, high need, may not understand time, may not be able to express themselves. And Low range: verbal, just need someone to check in with them, able to work outside of the home. Mr. Goulet asked where Asperger's falls into this spectrum. Ms. Dvorak stated that it is at the very low end.

Judge Romanick asked what is the number of people admitted to the LSTC with Autism, are the numbers going up, and are they not being released? Ms. Jenkins stated that 50% of the residents at the LSTC have a diagnosis of Autism and the LSTC is at 138% of capacity.
Ms. Thomason explained that DHS came to this meeting to listen and hear the questions of interest. She said that DHS has a lot of information to share but we do not have a presentation.

Ms. Jenkins explained the referral and admittance process for the LSTC. Every referral that the LSTC receives is a crisis. LSTC has a four-step diversion planning process.

- Step 1 includes confirmation of ID/DD eligibility, then the provider/DDPM team brainstorm regarding emerging needs, the DDPM contacts the Diversion Coordinator, then Diversion Coordinator contacts LSTC Social Worker.
- Step 2 focuses on emerging needs; if not resolved the Diversion Coordinator will provide a Cares application for the DDPM and provider to fill out. Then the LSTC completes a consultation call. Following the call, plans may include home/hospital visit, evaluations, and/or staff support into the home.

- Step 3 is about whether a person's needs exceed the provider's capability, if so the DDPM completes a Therap referral, if discharged from provider, a statewide referral is recommended. If under the age of 18, this needs to be reviewed by the Regional Review Team and State Review Team before LSTC admission would be considered. P&A would be notified that there may be a provider discharge. The DDPM must keep LSTC informed of all referrals that are denied. Admission to the LSTC is only considered after all other options have been exhausted. If all providers statewide deny the Therap referral, DDPM will complete the LSTC admission application.
- Step 4 includes the LSTC admission team completing an evaluation and will determine admission capacity. There may be times that the LSTC does not have the resources to meet the needs of the person or does not have capacity to serve them. At that time admission may be delayed or denied. Discharge planning begins upon admission with identified providers and the DDPM will initiate the Person-Centered Transition Plan.

Mr. Goulet asked what happens if the person is denied? Ms. Thomasson stated the pressure on the staff at the LSTC is very high to accept new admissions. Ms. Zietz said when P&A receives calls, they are in dire straits. The person is getting a 30-day discharge from their providers, and if other providers won't take the person, we are seeing people discharged to homeless shelters and the like.

Ms. Jenkins said we are beyond capacity at 138%. We have a lot of difficult conversations about if LSTC needs to make room to support a new admission. It is not easy; we have to make a lot of internal transitions to make sure that everyone is safe. We also think about what we can do in the community to help that person, what services can we provide to keep them at home, etc. We are struggling with the complex situations, supporting people with high needs and we are their last resort.

Ms. Thomasson said providers may think about discharging a person, due to self-harm, harm to others, and harm to property. This is often framed as aggression or violence. Often, the provider is to the point that they don't know what to do or cannot do it any longer. If the person is in a group home, and doing harm to others, then the police have to be called. Ms. McCleary shared that with her son, they needed two people to come and help in a crisis. We need more mobile crisis help. Crisis is a three-legged stool. Somewhere to call, someone to respond, and somewhere to go.

Dr. Kolstoe stated when I started at the LSTC in 1983, we could make a diagnosis of autism. But honestly, we didn't bother nor did anybody else in the state or the country or the world, at the time because autism wasn't seen as anything unique. Now the world is sort of flipped on its head that we have several people who are given an autism diagnosis. As we're talking about number of people at LSTC with autism 100% of those people at LSTC are developmentally disabled. So, trying to be really clear about the autism spectrum disorder is not an issue of a high volume of people with ASD are being referred to LSTC for admission as much as these are all people with developmental disabilities. The current practices of diagnosticians is to avoid giving the traditional diagnosis. For example, intellectual disability is a less attractive diagnosis

than the autism spectrum disorder, even if the person's cognitive performance is as diminished as the average person with an intellectual disability. In other words, the diagnosis would apply but the practitioner doesn't want to give it because of the autism diagnosis. In their mind an ASD diagnosis adequately explains the person's problem, and we don't need to add on the diagnosis of the intellectual disability. In order to be admitted to the LSTC you have to actually have an intellectual disability, as well a DD diagnosis because of how the statute is constructed, so the people that we're talking about having autism spectrum disorder at LSTC also have an intellectual disability.

Ms. Jenkins talked about the complexity in terms of the diagnoses that the person is given is not exclusive to autism spectrum disorder but it's also including their intellectual disability. That's part of who that person is. Ms. Jenkins described the challenge of getting somebody admitted to LSTC and said they take a great deal of pride at how hard they make it to be admitted to LSTC.

Mr. Kolstoe stated Ms. Bay's entire hierarchy of people under Ms. Thomasson's umbrella works together with Superintendent Jenkins, outreach staff, and himself to come up with a solution with providers. Some providers are more willing to work on it than others. Ms. Bay and her DD program managers across the state, work some real magic for people and that's going on all the time, its just that we get to see the ones that it's not working for. LSTC sees a range of problems from sex offenders to people with active schizophrenia which complicates things on top of autism diagnosis and intellectual disabilities of varying levels. LSTC has a psychiatrist that has been with there for almost 30 years, and he just retired. But he is hanging in there during his retirement, we're the only ones he's willing to serve. He has the best credentials in the United States for people with developmental disabilities, so we've got some tremendous resources. Mr. Kolstoe further relayed aggression and damage to things are horrendous issues for everybody to deal with, and while providers are very frustrated, they seem to be OK to refer those people to come to LSTC. It's not like LSTC does anything different than any provider, we all meet CQL accreditation standards. Probably our biggest problem in terms of challenges is the mental health system, believes that people with developmental disabilities shouldn't come to their psychiatric unit, and they've got some good reason to be skeptical because when they do admit them sometimes nobody will take them back.

Ms. Thomasson commented I think that's an opportunity that we've been talking about a lot as State staff, and do we need to find a research or clinical partner to say what inclusive behavioral health care looks like if you really want to allow people to live well in the community. So, let's say that you were a person with a mental health diagnosis, and you would benefit from participating in group therapy of some kind and yet the group therapy that's available, will say to you, "You are not appropriate to participate in this group therapy, because you have a cognitive or developmental disability." I think we have to figure out a way to have inclusive behavioral healthcare, that is inclusive of a range of disabilities. I don't know that there's resistance to it, but I also don't know that there's already a path to it. We have to think about how all the resources can work more inclusively, so we are helping people live well in the community.

Mr. Goulet commented about LSTC operating at almost 140% of capacity. “Now you've talked about physically abusive people that you might have to serve; how do you do that when you're over capacity? You have got to have burned out staff on your hands working with the toughest cases - isn't that what I hear by that number?”

Dr. Kolstoe said I'm not going to claim any more severe of a workforce situation than every DD provider in the state, or in all the industries in the post-COVID world. We do seem to be missing about 20% of our workforce that just didn't come back. We have the positions; we have the money. We just don't have bodies to fill those positions and our colleague providers around the state are in the exact same position. They don't know how to cover people. They've got somebody living in apartment with 16 hours of support a day and they don't know where to find the body to go fill that in even though they have the money. Maybe Ms. Bay can speak more to what their plight is, but we're in the same boat. And yeah, our staff are being burned at both ends of the candle, but so are provider staff. I don't want to claim any special status, but our staff have been champions through this. There's no way to describe how remarkable they are as a group of people.

Ms. Thomasson reiterated Dr. Kolstoe’s point that before COVID, we had shortages, but nothing like what we're experiencing now, and she think that plays into what we're seeing with the increased requests for LSTC admissions.

Ms. Bay commented I do have a couple points. I just wanted to let you know that within our DD system, we do not have an eject-reject policy. We ask that our community providers to provide a 30-day discharge notice, but that is not enough. The key, and where Dr. Kolstoe’s team comes in, is trying to identify issues before that 30-day notice is even considered. The Cares team, provide support across the state. Oftentimes the Cares team goes in to stabilize a person, as soon as things are improving practices return to normal, and suddenly another situation happens and the whole thing falls apart. Then whether it's provider or the family saying I'm done; we're looking at a 30-day discharge. We have a good start on a mobile crisis unit at each one of our human service centers. That's what we need, and it needs to be built up more. I think we're also seeing the fact that we've got a mental health crisis; we don't have enough mental health supports and the pandemic has worsened the situation. We need crisis response to be able to come in and deescalate at schools, family homes, and people’s apartments whether the person has a mental health crisis or a developmental disability. We need to spend a lot of dollars integrating our system, so we don't have people who can’t access services. We need a crisis response system that serves children and adults. This should minimize provider burnout.

Ms. Bay continued, we're in a unique and exciting time right now with the American Rescue Plan Act (ARPA) Funding, it's really allowing the department to think outside the box. DHS plans to use half of the money towards retention and recruitment incentives for providers in hopes of more people applying to be direct service staff. ARPA money will also assist with LSTC transition and diversion. We have a service in our waiver that is called family care option that is used very

minimally. This may be a tool for people to be able to stay at home if we can find workers. We also have situations where we need to expand our respite; right now, respite is only 20 hours.

Ms. Thomasson explained that different tiers of funding for host homes. We have adult and child host care in our system already, but it hasn't been revamped for years and we want to start revamping the host home system for children, and that will spill over into the adult system eventually.

School attendance also impacts the family and provider. It all is interconnected, and we haven't always been the greatest at identifying those connections and making sure that all the pieces are working, so if you hear nothing else today, I hope you hear that that we are trying to find a way to have stability through crisis.

Ms. McCleary stated we have a good start on a mobile crisis unit at each one of our human service centers. When you talk about being able to have it be something for everybody, that's what we need, and it needs to be built up more and right now. I think we're seeing also the fact that we've got a mental health crisis. We don't have enough mental health supports.

Judge Romanick asked about the involvement of schools with making a diagnosis. Ms. Bay stated involvement varies by school district. School personnel usually participate on the team for the student with a disability. Shortened school days seem to be present in many of the recent LSTC placements. A big part of why we are seeing so many youth needing services outside of the home and school is because the school is charged with making sure that a child can be academically successful. For example, the team may decide that for this child, two hours of school is appropriate, and then the child is not at school for the rest of the day and according to the school it is then the family's responsibility to provide care for the rest of the day. Oftentimes that is more than the family can bear.

Ms. Jenkins commented that youth under the age of 21 at the LSTC do go to at least a couple hours of public school per day, not all can handle a full day. It is built into their IEP and that's what we base it on. That's been a key factor in their stabilization here as well. After the age of 21 we look at the adult transition program, that helps them learn some of the vocational tasks.

Judge Romanick said I just want to make a statement after my last questions. There are many districts, and the response is varied. This tells me that Olmstead should say that there should be standard participation by schools. From my perspective on the Olmstead Commission, that is a problem.

Ms. Zietz stated as a Commission, we received this very specific letter and this specific request. We've had great information and discussion, but I don't know that as a Commission we're really in a place where we know the facts, so that we can decide how to respond to this letter. For us to decide what we may or may not want to do, it would still be very valuable to have some information on the population at the LSTC, including information on ASD and dual diagnoses of ASD with intellectual or developmental disability. Perhaps census and diagnoses data could be

further pared down by the behaviors that are driving people to LSTC, lengths of stay, and capacity information. The inquiry that was brought to us says these numbers are huge; that this is a problem, and we need to do something about it. However, as Commission we still don't really know the numbers.

Ms. Thomasson stated they need to get to the real issue, which is often, what caused the family or the provider to feel like crisis was at the level that they couldn't handle it. DHS is trying to figure out how to get good data that we can use to help inform the Commission's discussions. DHS will provide further information and data to be available at the next Commission meeting.

OLMSTEAD STAKEHOLDER ADVISORY GROUP:

Mr. Gulya shared the idea of forming a stakeholder advisory group. Ideally the semi-permanent group of individuals would primarily consist of persons with lived experience. The group would advise the Olmstead Commission with input on various items of interest and also formalize opportunities for input to the Commission.

MOTION:

A motion was made by Ms. Zietz that the Olmstead Commission formally establish a stakeholder advisory group and that Mr. Gulya report back to us on developing that at the next meeting. Ms. McCleary seconded the motion. Motion carried.

TOWN HALL MEETING:

Mr. Gulya also suggested having an awareness event with a panel of Commission members. Ms. McCleary commented she likes the idea of piggybacking off a DD Provider conference where there might be 500-person audience to get the word out or an evening session would work too. Ms. Horntvedt-offered to work this into the ALL Group and Self Advocacy Conference in August.

OLMSTEAD COORDINATOR PROJECTS:

Mr. Gulya stated he would like to have a discussion of annual goals. He also shared information on the proposal for bringing in a consultant to assist with the development of an updated State Olmstead Plan. The consultant is the Technical Assistance Collaborative (TACV) which operates out of Boston. They've been involved in revision formation of several Olmstead plans around the United States and have previously worked with DHS. The current Olmstead Plan is approximately 14 years old at this point. Funding for this project would come from the DD Council and Money Follows the Person (MFP).

MOTION:

Ms. McCleary made a motion to have TAC come in and do the work on the Olmstead Plan and Mr. Norrell seconded. The motion carried.

Mr. Gulya explained that the OC will be working with the DD Council to survey DSP workforce to examine recruitment and retention issues. The DD division will be going through the staff stability survey that one of the major quality assurance groups in the nation goes through. The

National Core Indicators (NCI) is the satisfaction survey on the consumer and worker side, which is done in 46 different states. It is used as a quality control component for a lot of CMS/Medicaid governed processes. North Dakota has recently joined onto that, but there's not going to be data until 2023. This workforce survey will be funded by the DD Council and will collect information on workforce recruitment and retention, weak points, and barriers to entry. Ideally, survey results will be appropriate for informing the legislature during the next session, in terms of how problems may be addressed. Currently Mr. Gulya is working with UND to develop the survey instrument.

FUTURE EDUCATION DISCUSSION:

Mr. Gulya noted the group previously identified wanting education on the 1915(i), the state plan amendment for Medicaid that deals with behavioral health. It was supposed to provide additional services for about 10,000 individuals over this biennium; however, implementation has been taking longer than anticipated.

Juvenile Justice was changed in the last legislative session; the Century Code related to Juvenile Court, which dealt with how non-criminal incidents with juveniles are referred out for service is transforming to a model for bringing those juvenile referrals online. It should be in final form later this year and may be a topic of interest.

FUTURE MEETING DATES:

We are going to look to move the meetings to the third Tuesday of the month. The meeting room at Job Service is booked through the end of the year on the previous scheduled Wednesday's. Mr. Gulya will move the date to July 19th and October 18th.

The meeting was adjourned at 4:36 pm