

Olmstead Commission
Meeting Notes of
October 30, 2019

MEMBERS PRESENT: Leslie Bakken Oliver, Wally Goulet, Scott Burlingame, Siobhan Deppa, Julie Horntvedt, Teresa Larsen, Senator Judy Lee, Representative Alisha Mitskog, via conference call, Carlotta McCleary, Honorable Bruce Romanick, and Dan Gulya

OTHERS PRESENT: Matt Schwarz, Jillian Schaible, LuAnn Baker, NDIT, Shelly Peterson, NDLTCA, Christine Hogan, P & A, Kirsten Dvorak, The ARC of ND, Nancy Nikolas-Maier, Aging Services, and Brittni Auch, DD Division/DHS

WELCOME BY CO-CHAIRS; INTRODUCTIONS:

The meeting convened at 10:00 a.m. with a welcome by Leslie. Introductions were made by everyone present. The membership list was passed around for corrections or additions.

REVIEW OF GOVERNOR'S EXECUTIVE ORDER (2018-05.1):

Leslie gave some background on the Olmstead Commission. After some discussion about the need to make some changes to the focus of the Commission, a Working Group, consisting of Teresa, Pam Sagness, Senator Lee, and Leslie was formed. In 2017, the Working Group examined how Olmstead looked in other states and how their Commissions were run. As a result, the Working Group recommended some strategic changes in Governance, Membership, and the Commission's Duties and Responsibilities. These recommendations were adopted in 2018. The changes to Duties and Responsibilities include: Advisory and oversight role; Focus on community education and integration; Facilitate solutions to resolve community integration challenges facing individuals with disabilities; and Employment, transportation, access to services, education and recreation.

The Commission went from one chair, which changed several times, to the concept of co-chairs that will facilitate meetings and lead the vision and direction

of the Commission, as decided by its members. Under Governance, a new home for the Commission was needed. Senator Lee was credited with recommending the Protection and Advocacy Project, an independent state agency that is well known as a place to obtain information and could be the point of contact for all Olmstead calls, education, training, and information and referrals. The former Commission was made up of state agency representatives. The Working Group believed that state agencies are an important part of the Commission but should be non-voting members only. They would not be expected to attend every meeting and would address the Commission by invitation when a topic required their input.

CONSIDERATIONS FOR DEVELOPMENT OF THE OLMSTEAD COMMISSION WEBSITE:

LuAnn Baker, NDIT, was welcomed to the meeting. She would like to gather information from the Commission and take the ideas back to NDIT in order to develop the Commission's website. The Commission should be thinking about the images, wording, colors, etc. that they would like to see on the website. The question was raised about Open Records. NDIT can close any part of the website as requested by the Commission. There may be sensitive material regarding an individual or his/her condition that can't be made available to the public. The website needs to be easy for the public to use. There needs to be links for education, Developmental Disabilities, physical disabilities, and aging. There should be a GPS map so an individual can get to where they want to go and not get overwhelmed. The information needs to be accurate and secure. The Commission's meeting minutes will be made available on its website. LuAnn advised that Usability Testing is done by NDIT on all the websites it creates. An interactive website would be helpful. A commentary section would allow an individual to make comments and there would be communication back and forth with the Commission. Chat boxes could be available. Clicking a button could route an individual to P & A or someone on the Commission. The question was raised on exactly how long it takes to set up the website. The basic website is already there.

The Commission needs to make some final decisions on how they want the website to look. What is needed from the Commission to take the next step? A

suggestion was made that the Commission look at other state Olmstead Commission websites and see what they have and make notes on what is liked and what isn't liked. It all depends on what the Commission wants to do as far as how long it will take to set the website up. The website can be adjusted as it is being built. An estimate of approximately three months was given as a window to finalize the website.

The Olmstead Commission website would stand alone but could be easily linked to P & A or any other agency. Senator Lee suggested ND Olmstead as an easy website address for people to find. We want to make it easy for people to search for it. There would be some key words used on the portal to locate the website. There could be a link from the DHS website also as people are accustomed to going there. There will be no wrong door to go through. LuAnn is happy to come back and sit in on another Commission meeting. The state's platform website is very easy to use, and is much like making a post on Facebook. The Commission will own the content of its website from a security standpoint. If possible, using a ND login for security purposes would be best. It would be nice if all appointed board and commission members had an ND login while serving. There may be Open Records requests received by the Commission.

The Commission will form a subcommittee of knowledgeable and interested members to work with LuAnn on the website. The idea of all Governor appointed boards and commissions receiving an ND login was discussed further. LuAnn stated that she would take this idea back to NDIT for further discussion.

OLMSTEAD 2.0:

Leslie provided an overview of what's happened thus far with the Olmstead Commission in order to set the stage for discussion of where we are going and how we want to get there. Olmstead was described as community integration for individuals with disabilities. States need to eliminate unnecessary segregation of persons with disabilities and ensure that persons with disabilities receive services in the most integrated setting appropriate. In the past, the focus and funding for Olmstead efforts has been on serving individuals with Developmental Disabilities (DD) and Intellectual Disabilities (ID). It was noted that the Americans with Disabilities Act covers individuals with all types of disabilities.

May 2016, the Department of Justice (DoJ), Civil Rights Division, issued a Letter of Findings (LoF) following an investigation in South Dakota involving allegations of segregation of residents in skilled nursing facilities.

This LoF got the attention of DHS in ND. DoJ is currently investigating ND for the unnecessary segregation of disabled individuals in skilled nursing facilities. An imbalance exists between the amount of state funds going to skilled nursing care and home and community-based services. Unfortunately, people are entering nursing facilities because there are no other resources or other options provided. The investigation is ongoing, and efforts are underway to resolve these issues, including settlement discussions.

It was noted that ND has wonderful skilled nursing facilities and that they are part of ND's culture. While there is plenty of criticism surrounding skilled nursing facilities, the bottom line is that they are needed by residents of our state that just cannot live in a home and community-based environment.

OVERVIEW OF DHS AGING SERVICES DIVISION'S OLMSTEAD – RELATED SERVICES:

Nancy Nikolas Maier, Division Director of the Aging Services Division was welcomed to the meeting. Long Term Care services covered by Aging include: Nursing Homes, Basic Care, Assisted Living, Service Payments for the Elderly and Disabled (SPED), Expanded SPED, Medicaid State Plan Personal Care, Medicaid 1915-c Waivers (Aged and Disabled and Technology Dependent); and PACE. These services all broaden people's choices in ND. The access point to receive information on these services is the 47 County Social Service offices across the state.

The difference between Basic Care and Assisted Living was explained. Assisted Living is a more social environment vs. medical, but an individual can purchase additional services. Basic Care is reimbursable under Medicaid, while Assisted Living is not.

Approximately 3-5% of ND citizens need nursing home care. There has been an increase in people under age 65 using LTC services. Individuals 18 and older can be served by Aging Services and they are all served the same. There are 3,000 individuals receiving Medicaid in ND nursing homes. Approximately 2,200 individuals receive services through HCBS.

North Dakota is overly reliant on institutional placement for its consumers and ranks 48th in ratio of institutional care to HCBS. ND is ranked 13th in the quality of care provided. Individuals do look state to state for the best possible care. Senator Lee expressed her concern about the number of rural communities in ND and the challenges they face in these small communities. She shared the success story in Steele, ND where they converted their LTC facility to Basic Care and Assisted Living.

It was noted that the DoJ investigation in SD focused on the state not giving their residents all of the options available, but just placed them in LTC facilities.

The question was raised as to why the HCBS program is not getting more referrals? Possibly due to the lack of 24-hour support. There are 1,200 Qualified Service Providers in North Dakota and they are having a hard time finding clients.

Discussion turned toward “caregiver burnout” and what options are available to caregivers. Respite care was explained. The Older Americans Act and the Lifespan Respite Grant both help caregivers who need respite services. It was agreed that respite services are under-utilized. The caregiver often has the feeling of responsibility and that only they can care for their loved one. Often, caregivers pass away before their ward or loved one. The need for caregivers to take care of themselves is stressed at every caregiver training provided.

The area of Adult Foster Care was described and discussed. These residences serve four people or less. Adult Foster Care is very popular in MN. This is a good option for a shared living experience.

Information on the Aging Disability Resource Link was shared, and it was noted that there is no wrong door to access services through Aging Services. It was

suggested that this information be pushed out to Legislators so that they can share it with their home communities. The Aging Disability Resource Link is not a 24-7 line, but 8:00 a.m. – 5:00 p.m. Monday – Friday. It was noted that 211 and Aging Services do share referrals.

Leslie advised that, as a result of the 66th Legislative Session, a new FTE (full-time equivalent) position was granted to the Protection and Advocacy Project. This resulted in the hiring of Daniel Gulya as Olmstead Coordinator. P & A was chosen as the dedicated Olmstead agency to provide education and training and receive Olmstead complaints. It was noted that Daniel has some great work experience and will be integral in the work that the Commission does.

Leslie asked for some feedback/comments from Commission Members on the new Olmstead Commission and where it is headed. Julie H. – Feels this is a good group and is excited for the direction the Commission is going. Carlotta M. – Feels the Commission is moving in a positive direction and will be a great benefit for ND. Siobhan D. stated that the 1915i will solve a lot of problems for HCBS – she shared some insight into the 1915i. Senator Lee – Previously, Behavioral Health Services were only available after incarceration, but not like that anymore. Covers all ages. Dan – Getting information about services to individuals during incarceration is critical. Working with inmates upon release, during probation, is all part of that continuum. Goal is to make it as seamless as possible. Scott B. – Very encouraged by what has happened so far. Started on Commission two governors ago. Very deflated at last meeting. Feels the Executive Order gives lots of direction moving forward. North Dakota can do this and is happy with the general direction we are going. Judge Bruce R. – Involved with disability community due to daughter - aging is a whole a different lane. A large percentage of people in the state penitentiary have mental illness. How do we determine who has a disability - is everyone in the same lane? Will the Olmstead Commission determine an individual's level of disability - everyone has a piece of the pie when advocating.

A lot of acronyms have been used today. If someone has a question about a particular acronym, be sure and ask.

OPEN MEETINGS/RECORDS REVIEW:

Sandy DePountis, Assistant ND Attorney General was welcomed to the meeting. Sandy explained that the Olmstead Commission is subject to the open records meeting law. Open records include all paper records as well as recorded information, e-mail, etc. If someone requests information from the Olmstead Commission, we must provide it, unless jurisdiction says you don't have to disclose it. Any record created is subject to an open records request. All personal notes taken at meetings are open records as well. A Records Retention policy is not in place for the Olmstead Commission yet, but this will need to be established. Executive Sessions for other entities are kept for 6 months.

Discussion was held regarding all individuals serving on boards and commission being given a nd.gov e-mail address. This has been recommended to NDIT. Sandy noted that this could be quite expensive (\$4,000 quote received for one of Sandy's boards). NDIT will need to be contacted about this issue.

Under Open Meeting Laws a quorum is present if $\frac{1}{2}$ or more of Commission members meets, not most of its members. If 5 members meet and business is discussed, this is an open meeting. If a quorum of the Commission is at a legislative hearing and business pertaining to the Commission is being discussed, this now becomes an official meeting. Any time that public business is being discussed this is considered a meeting. When two or more people on a sub-committee meet to discuss Commission business, it is a meeting and is subject to open meeting laws. Any part of a public meeting that is used to gather information to bring back to the Commission is subject to open meeting laws. If there is a quorum participating in an e-mail, discussing public business and Reply All is pushed, you are having a meeting.

E-mails to set a meeting date and time is ok. If there is any kind of other information provided in e-mail, do not press Reply All – don't give any thoughts or opinions – don't weigh in on discussion. Save discussions for public meetings.

If two Commission members talk one-on-one that is not a quorum, but if these two call a third member to discuss something then you have collectively involved a quorum outside of a properly formed meeting.

A notice of scheduled yearly meetings is good to set up, then they are not considered special meetings. You do need to stick to agenda items. A meeting notice must be posted where the meeting will be held and information provided to the Secretary of State's Office and to anyone else requesting meeting notices. Special Meeting notices should be sent to the Bismarck Tribune. There are no minimum meeting notice requirements. As soon as the governing body knows then the public should know.

There are some exceptions to the open meetings law. A meeting can be closed during executive session. You must point to the law that makes the meeting confidential, i.e. confidential records or some other exemption. If the law authorizes it, then you can close the meeting and go into executive session. Follow procedure and announce to public what the issues are. Sometimes a motion is necessary. If you audio record the executive session it must be kept for six months, no transcription is needed. Personnel issues are open records.

During the last Legislative Session, it was determined that communications with legislatures are protected. Discretion should be used when releasing information. Commission should contact Sandy directly if there are any other questions.

OLMSTEAD V. L.C. – Christine Hogan, P & A Attorney:

Christine stated that it is good to see a revitalized Olmstead Commission. She would like to talk today on the Olmstead Decision, what it is and where it came from. In 1999, the U.S. Supreme Court's landmark decision in Olmstead v. L.C. found the unjustified segregation of people with disabilities is a form of unlawful discrimination under the ADA. It was ruled that it was a violation of the ADA to unnecessarily segregate an individual into an institution to receive care when these supports could be provided in the community. Christine continued with the background and history of the Olmstead Decision. She noted that Olmstead challenges have been brought on behalf of many segregated populations. She

noted that “At Risk” people are protected, too. “At Risk” means people with disabilities who live in the community, but have under-treated behavioral health conditions that place them at serious risk of institutionalization.

It was noted that there are a lot of lanes from which an Olmstead complaint could come: MI – Elderly – 1915i – Children (EPSDT – Early and Periodic Screening, Diagnosis and Treatment). One size will not fit all in these lanes. There needs to be a wide range of options when it comes to community-based services. We can’t get caught in one size fits all. Choices and options will need to be made available.

A suggestion was made that someone be asked to come to a future Olmstead Commission meeting to talk about Positive Behavioral Supports.

Small towns in ND have a hard time recruiting professionals to provide needed services. There are 11,600 students in the West Fargo School District – parents have moved to that area because they want to be where the services are good for their children.

There is need for greater funding for the Money Follows the Person program.

Mental Health mobile crisis units are being placed in every region across the state. They were only in two regions before. Request For Proposals (RFPs) were put out at least twice for the mobile crisis units. A suggestion was made to have DHS come in and talk about DHS providing the services themselves, with some contracted services. It would seem important to have a Peer Support Specialist on the mobile crisis units to help prevent any unnecessary hospital admissions.

OLMSTEAD COMMISSION’S STATE PLAN; ND’S LEGAL OBLIGATION TO DEVELOP AND MAINTAIN A STATE PLAN:

After searching for concise information on how to develop an Olmstead state plan for ND, it was determined that there is a great deal of discretion that goes into each plan. Plans vary widely from state to state. The ND Executive Order states that the Commission is being revised to expand its advisory and oversight role, which didn’t exist before. The 2019 Legislative Session granted a new position for

the Protection and Advocacy Project, an Olmstead Coordinator, who will work on greater inclusion and integration of individuals with disabilities.

DISCUSSION TOPICS:

What does the ND Olmstead Commission want to look like?

Role of the Olmstead Commission as a partner with State agencies:

Olmstead Commission models in other states – appoint sub-committee:

Discussion was held on developing a Help Line or a Hot Line for Olmstead complaints that would be answered by our new Olmstead Coordinator. Teresa explained that P & A phones are basically answered 24-7 by either P & A staff from the Bismarck office or an on-call advocate. This includes holidays/week-ends. The on-call advocate would relay anything that appears to be Olmstead related to Dan. P & A's toll-free line is also answered by Bismarck office staff during the day. While there is no current protocol for receiving Olmstead complaints, P & A's Intake Staff could set up some protocol with questions so that the appropriate information could be obtained and relayed to Dan to follow up on.

A suggestion was made that the Commission talk more about what goes to Dan. P & A's Central Intake may not know it's an Olmstead issue so some questions or a benchmark for eligibility needs to be established. Establishing some definitions regarding violations that would be Olmstead complaints should be outlined. Leslie stated that the Commission basically has two things to look at. The Commission has a state plan that is very outdated. A subcommittee should be set up to look at other Olmstead Commissions in other states and pull together information from that research. The subcommittee looking at other Olmstead Commission state plans would come back with some recommendations for ND. A subcommittee should also be set up to look at what we currently have as a state; what are our current resources, i.e. agencies that provide services. These services would include healthcare, housing, employment, transportation, education (community services and supports). We would also want to know how these services are provided today. An example of DPI was given - what do they do? University Systems – what do they have – their resources.

Gathering information on how other Commissions are organized and what they do will be important. Do the Olmstead Commissions in other states receive complaints themselves or is there a staff person on board? Commissions will vary in every state. A previous subcommittee of Jake Reuter, Pam Sagness, Teresa Larsen, and Carlotta did look at 10 states each. Carlotta might have her notes, Teresa too. It will be good to look at other state Olmstead Commission models.

It was suggested that Dan be involved in all subcommittees. It will be important to gather policies and procedures from other states in order to develop ND's state plan.

Reference was made to Page 12 of Christine's PowerPoint presentation. "Limitation on Integration Mandate" – States can show a "reasonable modification" if: - the state develops a comprehensive, effective working plan for placing qualified individuals in less restrictive settings, and a waiting list that moves at a reasonable pace not controlled by a state's efforts to keep its institutions fully populated. In ND, DHS has always said that we don't have waiting lists; they are called something else. If an individual has a service plan and is getting services, they are not on a waiting list to get what they need, i.e. least restrictive, most appropriate living arrangement. The flaw in not having waiting lists is that there is a total unknown as to who isn't getting services they need. We need to look at what other states are doing as far as waiting lists go.

Service plans are customized per individual. An example of where a waiting is used at the LSTC was given. Everyone at the LSTC is scored. If the individual's score reaches 12 or less, they are considered ready for community placement. The scores are composed by information from the individual, parents/guardians, LSTC, and DHS. If an individual reaches a score of 4 they shouldn't be at the LSTC anymore, but numerous individuals at just that level have been on that list for many years. Maybe the individual wants to stay at the LSTC. Maybe there are staffing issues, i.e. no apartment or group home bed, or no provider literally in the state that will serve that person, so they stay at the LSTC year after year after year. This would be considered a waiting list.

This situation sounds like what happens in nursing homes. If the resident is rated at a certain level, nothing ever happens. Nursing homes are mandated to do discharge planning, but they aren't moving anywhere, even if they are deemed eligible. The state's system isn't working in this case.

The concept of a waiting list is being ignored in ND. Again, the LSTC appears to have a waiting list, they just don't call it that. It is important for the Commission to have a better understanding of the LSTC cases on their list.

Teresa offered to head up the subcommittee that will be contacting other states regarding their Olmstead Plans and determine if they have a waiting list concept. Carlotta also offered to be on that subcommittee.

ND needs to come into compliance. The only way to show compliance is to show that there is a waiting list. We need a comprehensive plan that has a waiting list. If ND doesn't have a waiting list, we don't have a defense. Having the waiting list concept is not the answer. It is only one issue. ND needs to be able to defend itself from litigation.

A suggestion was made that all the concerns the Olmstead Commission needs to address should be put into some type of a queue to be worked through.

If ND doesn't have a list, then we don't have a problem. It makes everything appear hunky dory. If there is a list, someone should be keeping track of the list. If there is a communication breakdown, it is up to the individual to ask the question; if the question is asked two or three times and they aren't getting a response, then they stop asking. It is the professional's job to move the waiting list along.

There is a Quality Assurance position at the LSTC that should be determining when someone is ready for discharge. The guardian also has a say in this process.

The Residential Decision-Making Profile was described and that if an individual reaches 12 points or less they should be eligible for community placement. There have been people with less than 12 points at the LSTC for years. Is the issue that

a provider just can't be found for them. This can be the case, there is just no place for them to go. This then becomes a problem for the state of ND.

Teresa, Carlotta, and Dan will set a meeting date and put out a public notice. Leslie will join this sub-committee. This will be a public meeting so anyone else interested can attend.

As discussed previously, there is great value in knowing what resources are out there for individuals with DD, i.e. housing, education, health care, transportation, recreation, employment. Depending on an individual's age and his/her diagnosis will determine what lane they are in. There can be numerous layers to go through. There are also services for adults with mental illness and substance abuse disorders, children with serious emotional disorders, and those with traumatic brain injuries. Vulnerable adults include the elderly that may also have a physical disability. The Money Follows the Person program was mentioned. There are some new housing projects in Fargo and Grand Forks that provide supported housing for people with mental illness. These would be good models to look at. There can be lots of barriers for an individual with a disability looking for services; they look, but just can't find what they need.

Scott agreed to head the Subcommittee to determine what resources and services are currently in place in ND for each of the respective types of disabilities we work with.

Discussion was held on what the Olmstead Commission's role and responsibility needs to be going forward. Advisory and oversight, along with receiving complaints that can't be resolved. Issues that come into P&A that can't be resolved after Dan has addressed them, should be brought to the Commission for further follow up.

The systemic issue of Early and Period Screening, Diagnosis and Treatment (E.P.S.D.T.) is not being fully complied with. These are children's issues that include mental health needs or things that are medically necessary. Services are determined by the E.P.S.D.T. budget. Often families spend a lot of money in order to receive E.P.S.D.T. services. This is a huge systemic issue. Services should be

based on the medical need of the child. This is just one area we are aware of that could be resolved. E.P.S.D.T. has not improved since the 1990's. We need to fix E.P.S.D.T. in order to use 1915i.

It was suggested that someone from the E.P.S.D.T. program come to an Olmstead Commission meeting. E.P.S.D.T. needs to be in place or ND will be hearing from the Dept. of Justice. The bottom line is that these children need to be served.

It was agreed that the Olmstead Commission's by-laws and plan need to go hand in hand. Dan needs some guidelines to follow when taking calls and serving clients.

The two sub-committees established will plan to meet and prepare information to bring back to the full group in January 2020. Some rules are needed by which the Olmstead Commission will function. A suggestion was made that the Commission start with its by-laws, develop a mission statement, logo and a vision.

Discussion was held on setting up a meeting schedule for the Commission. Everyone agreed that timelines are helpful to get things done. Quarterly meetings were recommended. Subcommittees would come back to the next meeting with any input they have gathered. Any additional special meetings will have to be announced as well.

Siobhan agreed to work with Dan and Wally on the by-laws for the Commission. Judge Romanick stated that he would help with the research on other state's Commissions.

DATE FOR NEXT MEETING: The next meeting of the Olmstead Commission will be scheduled in January of 2020.

The meeting was adjourned at 4:00 p.m.