

My name is Carlotta McCleary. I am the Executive Director of North Dakota Federation of Families for Children's Mental Health, a parent-run organization focused on the needs of children and youth with emotional, behavioral, and mental health needs and their families. I am also the Executive Director of Mental Health America of North Dakota, a consumer-run organization whose mission is to promote mental health through education, advocacy, understanding, and access to quality care for all individuals.

The reason for our comments today is to discuss the structure of the Children's Behavioral Health Task Force and the work that the state of North Dakota has to do for the children's mental health system of care. Suffice it to say, it is overwhelming, but in many respects failure to act is no longer an option. The state of North Dakota has spent the entire decade studying the mental health systems crisis. The Schulte Report from 2014 found that North Dakota's mental health system of care is "in crisis" and it was a self-imposed crisis caused by a lack of funding, a lack of diversified funding, and ineffective administrative policies. Schulte noted that the risks to the state were severe: states across the country were being sued for failing to provide community-based services or require that individuals seek only institutional care.

We discovered 2/3rds of North Dakota judges have admitted to sending adults into prison so that they could access behavioral health services. While many were beginning to focus on criminal justice reform and behavioral health services for adults, an even more alarming problem was developing with children. Children with serious emotional disorders account for 13-20% of the state's population in any given year. From 2011 to 2017, the number of children in the juvenile justice system with a serious emotional disorder rose from an already concerning 49% to an alarming 79%. In that same time period, the North Dakota Department of Public Instruction was gaining a better understanding about drop-out rates for students with disabilities. Students with serious emotional disorders had among the highest drop-out rates and some of the worst educational outcomes of the entire student population. While the Department of Human Services noted that was serving only 9.7% (or 2,200) of adults with severe mental illness in 2015, we did not receive data regarding children. We are serving less than 4% of children with serious emotional disorders (1,033). That is a terrible disparity. But that is not all. In 1993, the Department of Human Services released a report, a call to action, if you will, called "Forging the Future." In it, the Department of Human Services said that the state of North Dakota would need

to serve at least 3,503 children with serious emotional disorders in order to have an “adequate” children’s mental health system. Today, we are serving less than one third of that. In all actuality, that figure from 1993 would be an underestimation for two different reasons. Firstly, federal estimates for the percentage of children with serious emotional disorders significantly rose over the last 25 years and our expectations on serving that population also rose. Second, North Dakota has gained over 114,000 people since 1993. To be conservative, North Dakota’s child population with serious emotional disorders numbers over 22,000 and may number as many as 34,000. Again, we are serving 1,033.

Since the beginning of the national movement for children’s mental health in the 1980s, researchers, advocates, and policymakers have understood that these children encounter numerous public and private systems and that each of them need to be at the table when discussing these issues. That of course means that juvenile justice and child welfare are critical to addressing the existing systems crisis, because it has always involved them. As such, any adaptation or successor to the Children’s Behavioral Health Task Force must have adequate representation of decision makers from within juvenile justice, child welfare, education, mental health, Medicaid, Indian Affairs Commission, health, children’s mental health advocacy, and primary care that is trauma-informed.

As I stand before you, there is something that is obvious to families. There is no parent or family representation in this body. Therefore, we recommend future bodies address this problem. It is a nationally-recognized best practice to have family representatives with lived experience in the various agencies that are represented in this council or any council that shall arise in the future. Families do not want tokenism, with one individual expected to represent all families who have a myriad of experiences in the system of care. Instead, what we recommend is to have a parent representative for each realm of the system of care: a parent with lived experience raising a child with mental health needs in education, a parent of a child with mental health needs in juvenile justice, a parent of a child with mental health needs in child welfare, and so on. We stand by our previous testimony in which we said we wanted majority parent representation on any children’s behavioral health task force or committee. Not only is this shown to ensure that each system is appropriately advocated for, but also ensures that the mental health system of care is family-driven and produces outcomes for families. Families are the ones receiving the services and are

the most impacted by any decision made in the name of an agency or the entire mental health system of care. They have the most at stake and therefore are essential for any task force or commission on children's behavioral health to succeed. This recommended task force structure needs to be replicated at the regional level, in all regions of the state.

We desperately need to expand the representation of stakeholders in any committee or task force for children's behavioral health that is to come. The issues that are impacting the state are serious.

North Dakota has a legal obligation to provide children's behavioral health services under the

- **Americans with Disabilities Act (ADA) / Rehabilitation Act / Olmstead**
- **Medicaid / EPSDT**
- **Mental Health Parity**

**The ADA and Olmstead applies to kids too!** The failure to provide intensive home-based services violates the Medicaid Act and ADA/Olmstead.

#### **ADA/Rehabilitation Act/Olmstead**

ADA regulation: People with disabilities must receive services in the most integrated setting appropriate. Olmstead: Under the ADA, "States are required to provide community based treatment for persons with mental disabilities when

- The State's treatment professionals determine that such placement is appropriate,
- The affected persons so not oppose such treatment, and
- The placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities."

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

#### **Medicaid: The EPSDT Mandate**

States must provide "early and periodic screening, diagnostic, and treatment" (EPSDT) services to Medicaid eligible children and youth under the age 21.

States must provide any "necessary health care, diagnostic services, treatment and other measures...to correct or ameliorate...physical and mental illness and conditions" regardless of whether such services are specifically covered in the state's Medicaid plan.

### **Mental Health Parity and Addiction Equity Act (2008)**

If private insurance plans cover services for people with mental health or substance use disorders, coverage must be equitable with coverage for other health conditions.

- Limits on coverage (e.g., frequency of treatments, days of coverage) cannot be stricter for behavioral health services than for other services.
- Co-payments and deductibles cannot be higher for behavioral health services than for other services.
- If out-of-network coverage for physical health care, out-of-network coverage for behavioral health care.

**Affordable Care Act (2010)** Extends parity to plans available through state exchanges, plans available to Medicaid expansion population, Medicaid managed care programs, CHIP plans.

For children, the culmination of all the above laws and case laws requires services such as intensive care coordination ("Wraparound Services") child and family team-individualized assessment, intensive home and community-based services such as skills training, mobile crisis services, respite services, trauma-informed counseling, supported employment, mentoring, family and youth peer support, family education and training, substance abuse services, and flex funds for customized services.

North Dakota has always struggled with implementing even the most basic parameters of this law, but now we truly need full implementation of EPSDT as mandated by federal law. Currently a child must spend \$15,000 before they can access PATH Family Support. Case aide services are capped based upon a line item budget in EPSDT's budget managed by the EPSDT Administrator. When the budget is low then services are reduced regardless of medical necessity. That's not how EPSDT works, but in North Dakota that is a regular practice.

Across the country a number of states have utilized a 1915i State Plan Amendment to their Medicaid program. Often states used the 1915i State Plan Amendment as a result of settlement

agreements in an Olmstead case, other states used the 1915i State Plan Amendments to prevent potential litigation. We are aware of North Dakota's interest in pursuing a 1915i State Plan Amendment, as has been recommended as recently as the HSRI Report of 2018. We wholeheartedly support that endeavor. However, we were struck by the decision of the Department of Human Services to remove children and youth from any resulting 1915i State Plan Amendment. We strongly urge this body to recommend to the legislature that children and youth should be included in the 1915i State Plan Amendment. Lest anyone thinks that the case history of Olmstead only applies to adults, we warn you it applies to children and youth as well.

Over the years there have been multiple failed attempts at writing waivers, State Plan Amendments, and grants. Most recently was regarding the 1915i, which was originally written for children but it was never submitted. Ironically, the Department of Human Services killed that proposed 1915i State Plan Amendment because at that time the draft did not address the adult population.

We also strongly urge this body to recommend that the Department of Human Services apply for federal grants like the SAMHSA System of Care grant. The System of Care grant was designed to be a federal investment that helped build a state's children's mental health system of care. One central component of that grant was to have the different entities in the state collaborate to provide services to children in the community rather than in institutional placements. As we heard yesterday from Chris Jones, the goal is to bring things "upstream." When North Dakota had this grant, children had fewer encounters with law enforcement, fewer hospitalizations, many children came back from out of home and out of state placements back into their homes, and academic outcomes improved, and it saved the state a lot of funds in the process.

In the entire history of this grant, the Department of Human Services has applied for it only once---back in 1994. As I have said, we have long had an issue with repeated failed attempts to apply for grants. A few years ago, the Department of Human Services was in the midst of writing an application for the System of Care grant. Meetings with stakeholders had occurred. A short time after stakeholder engagement, the Department of Human Services decided to not submit the application. As you can see there are many opportunities to begin what the state is legally obligated to do that the state has chosen not to do.

Lastly, we would like to comment on the Children’s Behavioral Health Task Force Platform and Strategies draft regarding seclusion and restraint. We continue to argue for the need to have the Children’s Behavioral Health Task Force recommend to the legislature to pass legislation that creates a state-wide policy on seclusion and restraint, with the provisions we outlined in our previous public comment. We agree with the language and spirit of the first two paragraphs in the Platform and Strategies draft regarding seclusion and restraint. The draft correctly understands that this issue needs much more attention than it has received in the past. What is confusing, however, is the end of the third paragraph and the entirety of the fourth paragraph. The strategy section seems to substantially undermine the intent of the previous language by continuing to uphold the failed practice of leaving it up to schools whether or not they implement best practices regarding seclusion and restraint.

- “Nevertheless, the CBHTF perceives a clear need and expresses its commitment to move forward with interim steps to achieve incremental implementation among selective school sites that support such an effort.”
- “The CBHTF recommends that funding be sought during the 2019 Legislative Assembly to provide competitive grants to select school districts or schools who voluntarily (1) adopt and implement comprehensive seclusion and restraint policies and practices, incorporating those best practices that are either specified within the Seclusion and Restraint Task Force’s guidelines or are documented by some equivalent policies, and (2) provide sufficient assurances and action plans to ensure the establishment of safe and appropriate student behavior management and staff intervention policies and practices.”

I have two thoughts to the above sections of the draft.

First, with this method of school building by school building, school district by school district financial incentives, what is the estimated fiscal note and duration of those funds for full implementation by all school buildings in the 244 North Dakota school districts?

Finally, children are being traumatized or having their lives jeopardized by unnecessary seclusion and restraint or the over-utilization of seclusion and restraint. I do not think it sends the right message to provide financial rewards to those schools who *do not* traumatize or harm children through seclusion and restraint. This should be a basic expectation for our schools--not something that comes with a reward.