

**ND ICC**  
**Thursday, June 8, 2023**

**PRESENT**

Carolyn Kueber  
Jill Staudinger  
Tina Bay  
Kelli Ulberg  
Matt Nelson  
Danielle Hoff

Michelle Ragan  
Eric Gault  
Jodi Hulm  
Amy Casavant  
Kari Morris  
Shantelle Petroff

**STAFF:**

Jackie Adusumilli

Colette Perkins

**GUESTS:**

Welcome and Introductions  
Members introduced themselves.

Overview of Agenda  
Agenda was distributed.

**TOPIC: FAMILY STORY**

Nicole Maddock has 2 kids, ages 6 and 4.  
Weston 3/19 – typical normal pregnancy and birth, looking back signs of diagnosis at birth. At 10 months, tubes placed, and they didn't work and did another procedure to take out anodes had fever and throwing up and had RSV in Feb 2020. Dr came up and sceptic infection. As result of stay had liver enzymes and antibiotics and recheck. Got farmed out to specialists. Pandemic hit. Went to allergist and be gluten and dairy free and stop breast feeding and enzymes still elevated. Went to er and dr ordered tests and came back and recommended GI Dr in Fargo and visit didn't go well. So many things still happening so they went to dr mcdonough and Weston was 13 months old. He contacted them to E.I. they did a CK level, and it was 22,000 and normal under 200. Put you into MS route. Went to Gillette Children's and had a team meeting with the dr

and official diagnosis was in 2021. Degenerative neuromuscular disease. Becky Matthews was their experienced parent and she told them everything that was out there for them. Have their team and goes to Gillette every 6 months. Did some adaptive skiing this past year. Graduated from E.I. Now works part time as Experienced Parent with BECEP. DDPM called and she started crying and explained the process and so we really understood things. Weston is on a DD waiver. Get some in-home support and respite. Did partners in policy and that was great, last September went out to DC and met with congressman and Senator Cramer and talked about rare diseases and what the challenges are:

This group to talk to pediatricians about this.

Community engagement piece – who educates primary care providers? Individual programs and there is always change. Region VIII – stable child find system between med providers and early intervention. Core group of drs there forever and we would go to yearly staff meetings, hey we are here and get a lot of referrals. And new dr came on, they would train the new drs.

Recommended that we get a subgroup together to hit this hard to educate across the state. Collaboration with primary providers to understand about mental health issues but can bring in early intervention. Kelli said the grant is due next week. Continue ECHO sessions and these are well attended and are recorded. Better communication not only with drs but with the community at large.

Lack of physicians understanding, step back and look at the bigger picture, how to support parents, etc.

Dreams of Motion – out at Huff and it is free, and they have 2 sit skis. Sit skis come from Terry Peak. Bottineau has Annie's House owned by Anne Carlsen.

## **TOPIC: NEW BUSINESS**

### Early Intervention Budget

Tina displayed the budget report and review all expenditures, which were Part C. Next was pay point expenditures for home visits, consultations, and evaluations and IFSP within the Part C category. Discussion on referrals being high both for kids and adults.

Quarterly Budget Insight – Tina showed this information to the members, and it is dated 8/19 to 3/21. It wasn't duplicating the individuals.

Report all expenditures for all 4 pay points now. Give public a picture of where we are within our appropriations for the year. Not sure what quarter they are catching up to but not fixed to this format yet.

### CDC Developmental Milestones

Jill stated there was no meeting.

Figured out what milestones will mean as a part of our community education.

### Early Intervention and Early Childhood Special Education Public Information Campaign

This came up with Angela about the desire to have a general public information around early intervention, early childhood special education and still areas that physicians aren't aware of or parents not getting information. Looking at this is much larger endeavor. Look at this this afternoon and how to work in a way to support partners and able to share to all groups. Think about when we discuss priorities this afternoon. At this point, no dollar amount is attached to this campaign. We have some ARP funds we could tap into but not external.

### Legislative Update

Tina shared a DD Legislative Summary, which was sent to all DD providers. This will also be sent out to ICC members. HB 1043 – added a definition that admitted children; added serious risk of harm language. HB 1045 – focuses on ICFs; giving provider opportunity to have 3<sup>rd</sup> party review to pass life safety process. HB 1048 – clean up language to the Century Code to set up guardianship establishment fund and funding up to 100 and maximum amount is \$3000. HB 1051 – clean up language. HB 1091 – family foster care for children licenses, certification, and approves and identify kinships relatives. HB 1165 – things related to staffing provisions for COVID. HB 1207 – vaccine bills. HB 1244 – income tax credit for employment of individuals with dd or severe mental ill increased from 5% to 25%. HB 1263 – added option for courts for child to participate in IJP. HB 1478 - lots of testimony on marijuana. HB 153- this will be available for children birth to 21 on 7/1/23 adding family adaptive behavior treatment code to train families. SB 2012 – Provider inflation 2% each year and \$1 per hr. for direct care staff and indirect program staff in year 1; personal needs allowance from \$100 to \$135; C. G increased daily rate and increased capacity by 30; new early intervention position; new quality assurance/compliance staff person; autism waiver – voucher ends on 12/31 and transition into the waiver, which increased 195 additional slots and age increased through age 17 and new services which were paid for on the

voucher; waiver out for public comment with an 11/1/23 start date; MFW – 25 additional slots and annual allocation for waiver slot increased from \$18996 to \$25000; effective date of 10/1/23. Regular providers get a 3 and 3 each July 1. Child health insurance increase will be moved to 210% on the poverty level of 1/1/24. Kelli – behavior resource person – contracted for this and we collaborate with them, and they work with the schools and received spending authority to continue; behavioral health school grants was increased. SB 2052 – LSTC – clean up. SB 2079 – cleaning up century code – contract with MSU to offer modules and training to DD providers, hiring a consultant to study our training as a whole and we want them to look at our SDS world and create something that is better for our SD families. SB 2276 – create a cross disability council to provide feedback on implementation, planning and design of the cross-disability children’s waiver; and hoping the individuals that have higher needs remain in the DD waiver and those not needing intense services would remain on the children’s; and hiring a facilitator for this council and funding to hire a vendor to drive the work. Family Paid caregiver – bill started out we would have this and excluded the aged and disabled waiver. Created a pilot program of general fund and starts 4/24. Looking at tool to help us define extraordinary care. Looking at what other states have done, and we need to develop administrative rules. We are also giving a position for this and working on the announcement. SB 235 – FAS. SB 2345 – guardianship to create a task force to align the guardianships.

Infant Development Programs also received the 2% each year and the \$1 per hour. Right Track was also included in the inflation increase.

### ICC Member Updates

Jill – in Sept will be another Gramma to a baby girl.

Michelle – finished up spread around the state more; HIT had staff participate in it and brainstorm how to get new staff enrolled.

Carolyn – next week doing training with early head start coordinators and bringing in various programs across the state. Jackie will be presenting. HeadStart and Carolyn’s office collaborated and have a website.

### ICC Priority Setting Activities

Carolyn – It just isn’t the ICC that this is happening as I sit on other groups, and this is happening there also, trying to figure out how to re-engage,

Michelle – budget subgroup – exp parent program to be cut and this was a good use of time to support the state office, building up to legislation and this could use some support, we want to advocate for what is needed,

Jill – early intervention passionate. Streamline systems, ser easy for families and resources are interconnected, working together to serve ND citizens, provide input from the ground level up, keep my feet in it, first program to pilot programs, love to help be a voice for the state office, work to coordinate and collaborate across the state no matter where you live we find child eligible more consistency,

Eric – joined council new to being apparent, disabilities, role on the council, offer perspective form parents side and advocacy,

Tina – t.a. this helped us, we write stuff and hope it works, don't like to come and just report, like connection to providers and families, and do more how we structure this committee, family stories are helpful,

Jodi – get the most out is what the providers are doing, appreciate eh feedback, what are the frustrations, what can I change, we don't get feedback unless it is escalated to the highest power, hope that if you have issues you can contact me

Parent – a lot of families are underserved as we are rural, lucky we received a fast diagnosis instead of months/years, we need to be better at helping families.

Amy – wanted to be here to share my experiences and trickle down, doing zoom – give you my number to reach out and talk about this; I was parent and a provider and there are breakdowns, don't focus on what is going on in each region and each office – we are disconnected with them.

Matt – In Williston, I wanted to represent other parents and my community, and I wanted to learn things to bring back to the community. Now living in Grand Forks, I'm less connected to the community I represent, and I struggle with how best to contribute to the ICC. We're often told that parent perspective and input is important, but those of us who don't also work in Early Intervention may have trouble bringing our own skills or knowledge, apart from our direct experience as parents, to the table. With no guidance from the ICC as to how we parents can advise and assist Early Intervention

programs, I tend to latch onto little things that catch my attention but may not be useful. I want to know how the ICC can best advise and assist, and specifically how I and other parent members can be of use.

It's become clear to me over the years that we need a more diverse group of parents in the ICC. If parent input is so important, we should include some of the many voices who can't afford to volunteer their time, and we should ensure that parent members are being paid for their time just as all the state employees are. This proposition has consistently been shot down over the years, making it clear that, despite whatever lip service they may pay, the value of parent input extends only as far as it doesn't cost anything, which means its actual value is closer to zero.

I do enjoy being part of the ICC, particularly the in-person meetings where we can connect by being in the same room as each other, as well as talking informally during breaks and at lunch. In these days of mostly virtual meetings, I'm not getting that nearly as much, and so it's even more important to me personally to find a way to do something useful as part of the group.

Kari – what can we offer as we don't deal with early intervention; we have parents come and talk to us about a prior auth, insurance not covering; we regulate insurance companies, we are consumer driven, we do not regulate providers, Medicaid we refer to the Medicaid office, if there is something we could offer more of please let me know,

Danielle – being a voice for the families we work with, fun working with families, love the idea of partnership and collaboration, make sure kids have the best opportunities to survive, how can we change things from the ground up

Shantelle – passion for early intervention but for any individual who has a disability, got on as ICC needed someone as a DDPA and volunteered and had more infant development background, really important streamlining processes – creating consistency across the state is huge, I bring things back to share with other DDPRAs and get their feedback to bring back here, get calls all the time for referrals for infant development, kids turning 3 and adults, I want to get people the support they need

Jackie – started working with individuals with disabilities at 13, not being in with families so I need to hear what is happening, coordinator collaborates with existing programs.

Come up with 3 or 4 priorities to focus on this year.

Public information campaign

Community & family engagement

Committees – do we need to change them, make adjustments,

Commit an entire meeting to a priority and delving into it and develop a good plan to move forward.

Streamlining systems – be an umbrella.

Disconnection – PIEPs don't know what the ICC was; questionnaire on what would you like to see from us.

Enhance referral sources

Educate about early intervention

How to sustain and not be a one-time thing

Dickinson – Sanford clinic, added a component about being involved with early intervention or right track.

Meeting on parent rep/family story, streamlining,

Community of practice for everyone in the field – you talk to your own people, no crossroads, don't meet/connect with other providers across the state,

Jackie's screen addition:

Specific concerns with eligibility, specific concerns with funding,

List of people that refer children to EI

When a parent is referred, we don't ask where did you hear about that.

Parent panel – broader sample from parents. ICC could provide names to Jackie. Start a parent panel at the parent leadership group.

Behavioral Health role on the ICC – different opportunities or collaborations. We want to get more early intervention – getting resources and supports, meet with right track providers and resources available. We

are branching into family peer supports – can we support more as we are going into this. What is my role and what can I bring to this group.

Services that Behavioral Health offers:

Systems of care grant

Community Connect

Kelli could check into this by having a proposal submitted for her review.

What do you want

What are the goals

What is the cost

COLLABORATION

What do we want to do as the ICC:

Positions open – Jackie will get this list

How are other boards compensating members

ICC Parent compensation

Training New Members – Sarah Carlson – inform her of today’s meeting and how this group would fit into