

**ND INTERAGENCY COORDINATING COUNCIL**  
**Thursday, June 13, 2024**  
**Quality Inn, 1030 E Interstate Ave, Bismarck, ND**

**PRESENT**

Amy Casavant  
Matt Nelson  
Jennifer Withers  
Kari Morris  
Danielle Hoff  
Sarah Carlson  
Mariah Hill

Angela McSweyn  
Eric Gault  
Kelli Ulberg  
Michelle Ragan  
Jill Staudinger  
Missi Baranko

**STAFF**

Jackie Adusumilli  
Jordan Anderson  
Colette Perkins

**GUESTS**

Kayla Stastny  
Misty Bouilly

**TOPIC: WELCOME & INTRODUCTIONS**

Amy Casavant welcomed every to the meeting.

**TOPIC: APPROVAL OF APRIL 11, 2024, MEETING MINUTES**

A motion was made by Eric Gault and seconded by Mariah Hill To approve the April 11, 2024, meeting minutes. Motion carried.

Next meeting we want an update on Waiver Slots.

**TOPIC: PARENT REPRESENTATIVES**

Amy talked to a grandmother and former DDPM who has a grandson with autism. She asked if the son and/or wife would be willing to join us; they both work 2 jobs. The Grandmother said she would come and present. Amy and Jackie talked about getting this approved and should we encourage this as a Council, having a grandparent on the Council. It

wouldn't replace a parent representative, it would be another position on the ICC. We would have to ask the Governor's Office permission to appoint them based upon; how it is written in the fed regs. It would give additional stakeholder/consumer input.

Matt's committee is working on updating the Standard Operating Procedures and we will look at the current language. What about adding guardian; what about caregivers? Parents in the federal language is defined as caregiver/guardian/foster parent/grandparent. Trying to get something scheduled to discuss this with our TA provider. Rachel, who presented a family story last time, is interested in serving. Sarah shared the application with her. Steph Nelson, who is with Anne Carlsen Center, is more involved in early intervention and interested in participating.

Angela asked if we know what the root cause is of our difficulty in hiring parent representatives? Is there marketing we can do to help with this. This hasn't been done but would it be a good idea.

Stipends for parent representatives. We approved the raising of the stipend but we are revising Operating Procedures and figuring out a child care amount. Child care will be for every parent.

There was discussion on a one page flier to take to home visits about the ICC. Professional development to grow our own knowledge also. Phone calls or in-person with potential parent representatives and talking directly to the potential parent. There was discussion on raising awareness to the public. Have members to share this on Facebook also. What about using are partners: ASPIRE, Pathfinders, Family Voices, Designer Genes, etc.; to put information in their handouts/newsletters about the ICC and looking for parent representatives.

Follow up – create a flier with a QR code that DD Program Managers and providers can give to parents.

**ACTION: Jordan will develop a flier and send out to the members to review, comment, and/or approve.**

Our focus is on parent representatives. Could we open a position to general public to advance voices? See no reason why we couldn't include

the 20 to 30% of parent membership that could be the non-traditional roles; include a child over 12; guardian; caregiver; etc.

Amy has 2 possible replacements – which she will give a flier to.

**TOPIC: OVERVIEW OF AGENDA**

Amy reviewed the agenda with the members.

**TOPIC: FAMILY STORY**

Local family had the incorrect date but will present at the Sept meeting. Found another story but they had a hospitalization and Sarah got permission to talk about their family.

Sharing family story to be motivated about what to change when things don't go as smoothly.

Ty, is supported at Mayo, from Burleigh County, born at Sanford and very very early - 1 lb. and 14 ounces. 4 months in Bismarck and then transferred to Mayo and there 7 weeks and on a vent; but not ready for a home vent, has Gtube; brain and heart doing great. Needs respiratory support and is a big hurdle for families. They live in a rural community. Need nursing support around May 1st. Nicole has applied and has a DDPM. Hospital is discharge planning. They explored ACC and other avenues. Ty is not screened to the waiver and not yet receiving early intervention services. Sarah said he would be screenable. ACC doesn't have openings. What would nursing services look like and their private insurance wouldn't pay. If DDPM can't help fill out Medicaid Application then family should be referred to an Experienced Parent. Share with huge pride the services ND offers and it shouldn't be so difficult for families.

Kelli talked about how we need to help solve system gaps and barriers to better serve children and families. How do we get Medicaid to train other people that answer the phone and being more knowledgeable. Do we have a visual of how this should work and if it didn't happen, who is responsible to work with hospitals so that social workers are doing things correctly. Do we have a strategic plan to reduce barriers for families? Ty would be qualified for Part C services on day 1; but we don't have a means to deliver the services in the hospital and we need to figure this out. What part of the DDPM role is it to make it more goal centered – purpose of IFSP

– goal would be is he getting all services that he is eligible for? A DDPM is checking in on the family.

Jill stated that there are inconsistencies in DDPMs, some are more comfortable creating IFSP in hospital and others say lets do this after you leave hospital; don't know how to write the plan. It is their job to dig into social security, Medicaid. We don't have experienced parents across the state to do this. What about a State Experienced Parent that navigates the support and billable service. Very appropriate place to help families navigate. Haven't seen DD world doing this outreach to hospitals.

Can we streamline the call center for our specific families? Schools are experiencing the same thing.

Amy discussed a situation she had and that she talked to her legislator and got a name and number to call, and she did and the issues went away.

It is critical that the application is filled out correctly. Child is on DD waiver, have to use generic disability form.

Application process is critical to the work we do for the Council and helpful to the DDPM to complete the application so that they aren't badgering the family to complete the application.

Jackie stated there are issues with regions as far as Medicaid asking for more information, even if they have the slip. Eric stated they ran into this when renewing their Medicaid and case worker refused the application as it didn't have the income application their child. They wrote on application that she is on the HCBS waiver.

Reach out to train the DDPMs to develop the IFSP when baby is in the hospital. Jackie said we will get on the schedule to do this training.

This should be a priority for us/a goal!

Purchased training around the HELP for the DDPMs and in process of training.

**TOPIC: NEW BUSINESS**

## Supporting State Initiatives

Parent representative –

Working on reviewing the Standard Operating Procedures.

Compensation options for parents – needing childcare and not lose out on wages and work on sorting this out.

Technical assistance came available – reached out to Matt; set up meeting time and move forward to make changes.

Membership committee – worked on the orientation binder. Sarah said the group hasn't met. Maybe this committee can help with the flier.

Focused previously on the family stories, create a welcoming packet – have cards we started with – glad you are here/piece of gratitude; need to revisit the terms and little about what the ICC does.

Increasing Public Awareness – having unified message about early intervention, what services are available, promoting the ICC as something to be involved in and the benefits of being involved; consist materials across the state and get into the hands of primary referrals sources – medical people. Jackie stated they are working on translation of the materials and partnering with the preschool development grant to do this. Brochure about early intervention. and available in multiple languages – Jordan will be working on.

Formalizing and strengthening collaboration –

Referral site to hop on to.

Membership – what really is the purpose of the ICC – if we are training people coming on the Council and to be able to express what we do, what are role is as a parent representative. Parents need someone to tell them/us how to be useful so that we are useful to the ICC.

Should we get advice from the Governor Council on what to do.

Partner with DPI and give annual orientation – dedicate the Sept ICC meeting to just be orientation.

Discussion/Review of Current Initiative

Future Initiatives Planning

One thing that we want to plan around – knowing your purpose on the icc and is it for and ease of access for families.

The online materials are being developed and as Jackie is back she will continue to work on them.

Defining icc roles/personal orien

Access for families – move forward and portal with information and referral

## **TOPIC: STANDING NDICC AGENDA ITEMS**

### ICC Member Updates:

Michelle – if re appointed can't take the chair position.

There is a DDRPA that has applied to replace Shantelle.

### Committee Reports

#### Standard Operating Procedures:

Talked with someone from ICC in PA – have more funding and go to conferences and better sense of what they are being paid. Need to come up with a number that we can support and bring back to this group.

Family Survey Committee will meet in January to finalize recommendations.

Will convene membership committee and would be willing to review the flier.

Hear something from a family to bring it to the attention of the ICC members.

Brandi Pyle is the appointed legislative representative. Encourage her to let Jackie know about bills pertaining to us. Jordan will ask the ND Home Visiting Coalition to send their legislative information to the ICC members.

Do DD providers include Part C issues during the legislative time?

Get condensend/targeted information out to members.

Potential Council members are sending in their paperwork and is it being received by the Governor's office. Jackie has asked for confirmation that the paperwork has been received.

What do we want in the portal – enter information and make referral; put in address and get a number to call. Figure out funding, technology, how to train people. DD wants the ICC to assist us in developing an online portal.

What initiatives were recommended and what was accomplished that the state used.

Create portal recommendation, you check into funding and then come back to obtain what we want/need in a portal.

Who makes a final decision on a portal and if and when it can be done, what is the process to get a portal going.

We are asking how we can be impactful; want my time to be useful; want the work to have meaning and purpose for the state office so families and babies have better service.

Need to talk to our IT Dept to find out what is available.

Can referral go into one spot and then triage out.

Parents enter information and professional makes the referral.

Building system they enter their name, address, phone, and it goes into the system and then it goes to a region.

They say they are ok with texting or email or call.

Family access to Therap is an option – it is a capability.

Portal – basically they enter their information and system would determine who it goes to; and then human touch starts after that.

NICU referral – tell all social workers/physicians/etc – it will send parents here, here is a QR code and do on day 3.

Put the early intervention provider information on the portal.

Put the IFSP out there also.

Jackie said maybe we could ask to see a test of the parent access from Therap.

Good starting point if parents can self-refer.

Link for complaints about providers.

## PARENT REPRESENTATIVE ROLES

Want to be helpful; parent navigation on a website would be useful.  
Develop a list of ICC accomplishments.

People recognized and feel valued.

Why do you do what you do – in our professional role; why interested in your profession; what is the reason you keep going back to work; agenda item of celebration and reflections; what are we taking away from a previous meeting and what did you reflect on; requests from state with expectations - could give us a sense of purpose – it is very open but doesn't give you direction.

**Jordan will send the other state's ICC website to the committee members to review.**

What initiatives are other divisions/depts working on and how does that affect the ICC?

What about a case study – brainstorm ideas/suggestions to the person that brought the case to the group.

Jackie stated it is beneficial to plan a year and help orient everyone to the purpose and look at the structure of the agenda and desire to add in other regular standing items – guest speaker and on the topic of the meeting and outside comments.

Sept 11 will be priority setting and they will be sending Jackie further information.

The Part B and Part C shared meeting – seems to be more Part B sharing. Would like to see things more discussion pertinent to both of us. Not discuss high school; transition C to B; discuss more things we have in common; have each side bring a family story; data about our kids coming into early intervention and not into Part B are they picked up later.

When a family has a child on an IEP, that we give them a Right Track brochure. Do an overview on Part C? Discussion what we have in comm, when needs to be changed, etc.

Spend an hour after lunch to discuss shared topics. Give update on transition for the 3 to 5 program – trying to work together to keep data seamless.