

**ND INTERAGENCY COORDINATING COUNCIL**  
**Thursday, February 8, 2024**

**PRESENT:**

Shannon Grave  
Missi Baranko  
Mariah Hill  
Michelle Ragan  
Shantelle Petroff  
Danielle Hoff  
Jennifer Withers

Louise Greff  
Jodi Hulm  
Matt Nelson  
Karri Morris  
Angela McSweyn  
Jennifer Grabar  
Sarah Carlson

**STAFF:**

Jordan Anderson  
Jackie Adusumilli

Colette Perkins

**GUESTS:**

Mistie Bouilly, Pathfinder

**TOPIC: WELCOME AND INTRODUCTIONS**

Amy Casavant, new chair, introduced herself. Amy had the ICC introduce themselves.

**TOPIC: OVERVIEW OF AGENDA**

Review of the December 14, 2023, meeting minutes.  
No changes were suggested for the minutes.

**A motion was made by Louise Greff and seconded by Missi Baranko to approve the minutes as distributed. Motion carried.**

**TOPIC: FAMILY STORY**

Charles and Brea Tatum.

Harlow born with CDH; missing 80% of diaphragm on the left side and heart pushed to the right side of her body. Liver and stomach was risen to her chest cavity. Put on medicine to oxygenate her blood for a few weeks. She is 4 and going to preschool. In the hospital for 228 days and came home with 10 surgeries. She actually died when she born but they brought her back to life and 2 days later tried to put a tube in her side for her lung

and nicked her heart and had to brought back and do heart surgery then. Brea shared some pictures. Came home on oxygen and G-tube got off of oxygen on 2<sup>nd</sup> birthday and still has the G-tube and only drinks water by mouth. Has a team working on getting her to eat again. Cousin told them to contact Sarah Carlson and she helped them get set up with early intervention. Preschool teachers says she knows things academically. Putting words into action is being worked on. She was in the hospital during COVID and the riots. Never left Harlow alone. She goes with the flow and will repeat a lot of things. Therapy 3 times a week. Early Intervention did the one monthly meeting to see how she was doing. Michelle gave them a book of pictures of Harlow and she looks at it. She will do preschool again next year. Outreach was amazing. Everything is going very well. Brea said she was impressed. They set us up with Ashley at first and she was great. Going to BECEP preschool went very smooth and met the teacher right away. Don't remember if earl intervention was set up before they left MN. Within the first 3 months connected with DDPM and got Medicaid going. Angela thanked them for sharing their story. How did you handle the stress of dealing with this. Brea's Mom really came through and helped. Brea's job is very family oriented. When Harlow came home, Charles decided to be a stay-at-home Dad. It was nice that it was us telling people about our daughter, not them telling us about our daughter.

## **TOPIC: NEW BUSINESS**

### Early Intervention & Early Childhood Special Education Public Awareness Campaign

The members were divided into 4 groups and each group was given a topic to discuss and then report back on.

**1<sup>st</sup> room** - NICU and hospital referrals and support provided in hospital to early intervention.

Discussion getting referral information to the DDPM and getting referral into the NICU and hospital. Talked about the process and DDPM will reach out and hospital might say family is going through a lot right now and call when they get home, and we are saying no we need an experienced parent in there now.

Good to have electronic file with the referral forms, lots of turn over with social workers, and a central location they can go too.

Better state website for parents to access and what is available to them.  
Poster for NICU or birthing room or having a QR code to click on.  
Forming a committee/group and meeting even 1 time whatever it takes,  
with someone from ICC and DDPM for each region, about the process and  
ensuring it is getting done and explain why the family needs us. More ways  
for families to reach out, especially outside of business hours and have  
access to people's emails.

**2<sup>nd</sup> room** - information to providers and parents.

Really great discussions and productive

Getting more information on what the ICC is in a parent friendly way –  
either handout/brochure and making sure that is parent friendly and giving  
out at the intake or annual IFSP & DDPM hands out

DDPM to report if family is interested -

Making sure parents know it is a first point of advocacy and gets them  
connected to other parents.

Talked about families and on the brochure list ICC meeting dates and how  
to attend – put it is a parent and professional meeting.

On the brochure list what the parent role is, what membership leads to,  
sending parents to other meetings and talking about ICC and what we do  
and sharing open positions.

Treating ICC as stepping point, even just having parents come to a meeting  
to listen and why we want people to know what it is. Part of the DDPM  
training to know about the ICC and then share it with parents.

Application to join ICC on the website to be a prominent link on the ICC  
website. Getting applications and bring to the executive committee so we  
reply right away. Printed material for the website to explain what ICC is.  
Need to figure out what the parent role is and put in the printed material.

**3<sup>rd</sup> room** - early intervention referral service and how to educate and refer.  
Educating referral sources.

Who some of those people (referral sources) could be statewide

Needs to be a statewide plan and effort to have materials and that we have  
the same message and information to give out.

Inconvenience of a phone call is not helpful.

What does it take to do a single point of entry redesign – QR code, the  
website is it not super family friendly to refer child and most families don't  
know the wording.

Something to go out to all potential referral sources.

Reaching out to child welfare on statewide level and confusion on early intervention and healthy families.

**4<sup>th</sup> room** – talking about DD waivers to the public and parents.

Talk education about early intervention to everyone -stakeholders and parents.

Single referral area – took away mystery and say my child needs help and back end that work is done for the family and family is contacted by the most appropriate group.

Single referral system is part of the SSIP – this plan is for early intervention – able to bring in other health and human services entities outside of early intervention.

Educating primary referral sources – hospitals and their social workers.

And talked about turnover and the struggle with that.

Social media usage and how to tap into partners to get general information out about early intervention – Pathfinder, home visiting coalition, etc., and HHS.

Different hub or number to call for help/assistance for families.

**A motion was made by Michelle Ragan and seconded by Jody Hulm that the state creates online and physical materials for distributing that provides a consistent message for education and marketing. Motion carried.**

#### Part C Federal Reporting

Jordan, Kristen, Carol, and Jackie worked together to submit the APR.

APR submitted to OSEP by Feb 1.

Added some great content that we added.

OSEP will review and reach out to clarify if they have questions.

Usually, we receive our final determination around June and then we will share that with the group.

We turn around to local programs to issue Letter of Findings. This year that has 3 locations that received no findings. Every other program received 1 incidence of findings. Next meeting more specific information will be shared with the ICC.

We had 4 programs that had needs assistance. These will be posted on the website in March.

Part C grant will be submitted in early May, there will be time for public comment, and then our grant funds will be received.

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

### ICC Member Updates

Matt – update on deadlines for DEC – conf is in New Orleans and earlier and anyone thinking about doing presentation proposals are due Feb 15 from today and if wanting to be a viewer that deadline is Feb 11.

ND Cross Disability Advisory Council is seeking public input, and this will be done virtually on Feb 15. There are 2 opportunities to participate: Noon to 2pm or 6pm to 8pm central time. Jody put the link in the chat. Jackie has a flier, and she will forward to the ICC members.

DD Waiver period 5-year period is ending for the current time and the new waiver goes into effect 4/1/2024. Proposed waiver is out there, and changes are highlighted.

Autism Waiver approved – was up to age 15 and now it is up to age 17 and increased the number of slots by 195 and now there is a total of 345 slots and did a revamp on services.

Jennifer Withers mentioned that DPI is continuing their partnership with the Waterford. Jennifer stated that she will send out the invite to the ICC members.

### Committee Reports

Committee talking about appropriate childcare and parent compensation, let Matt know.

Family Survey Subcommittee – Jackie asked Sarah to have the group meet and include Jackie to talk about tracking the family survey returns again. Sarah will include Jordan also.

**Next Meeting is Thursday, April 11, 9am to 12pm and it is Virtual.**

Meeting Adjourn