

INTERAGENCY COORDINATING COUNCIL
Sept 25 & 26, 2019
Quality Inn, Bismarck

PRESENT

Sarah Carlson
Tina Bay
Shantelle Petroff
Janelle Middlestead
Kim Hruby
Shannon Graves
Kelli Ulberg
Angela Shull

Mary Haugen
Moe Schroeder
Matt Nelson
Chris Pieske
Jodi Hulm
Jill Staudinger
Becky Eberhardt

Staff:

Jackie Adusumilli
Colette Perkins

Introductions were made.

Have to be appointed to vote.

TOPIC: FAMILY STORY

Garrett S., wife and 2 daughters.
Want to give back and support other families like we were supported.
Informed baby would have a complete cleft palate.
Wife went into planning mode and found Kim at SHS.
Thanks to newborn screening process congenital heart defect was detected. Made appointments with cardiologist in Fargo. Early intervention program helped us to feed her. Cleft repair went really well. Started to eat well but then deteriorated. Had open heart surgery at 4 months of age. Ended up with a feeding tube. His wife was diagnosed with stage 3 breast cancer. Early intervention and all supports were a huge help to come into our home and help us

coordinate feedings and schedule things and future path of care for both. After palate was repaired, needed to get her developmental delays addressed. Having someone come in and help with speech is a blessing. They received specialized care from people that truly cared. His wife has developed lasting friendships. This helped her to develop socially also.

Nothing but positive experiences.

Simplification of paperwork would be good.

Online forms are best.

Training medical professionals/nurses to make these programs aware to us rather than us trying to find them.

Missi B - Healthy Families expanded around the Dickinson/Watford City and diversion program, family strengthening coach - birth to 21 struggling with navigating services and to avoid more intensive services, it is voluntary and free. Healthy families in Watford City and Dickinson have about 6 staff. Provide home visiting services to the women's correctional center to those ladies that are pregnant, etc. Right Track Coordinators meet quarterly with Jackie and they are very appreciative of this opportunity.

Tina - within the next month, putting Waiver out for public comment. Nothing in Waiver to help provide with nursing component for medically intensive. Will be requesting an increase in our capacity.

Shantelle - fully staffed now plus they have intern.

Janelle - Division can review claims not being covered or denied, they can do that, through consumer assistance. There are caps - expedited reviews within 72 hours of denial or within 45 days.

Kim - Special Health Services (SHS) can provide families with gap-filling financial assistance for treatment that primary insurance may not cover. The maximum amount of coverage is \$20,000 per year. SHS has also started a Newborn Screening Long-term follow-up process that allow a nurse to provide care coordination and linkage to services for babies identified with a medical condition through the newborn screen. In turn, Early Intervention referrals should increase due to this new process.

Shannon - offering program earning early children degree and take dual credit to get early children special ed degree and try to lessen the cost to people.

Angela - learning and taking it all in. PDG grant - 18 activities and 5 overall goals and developing needs assessment and strategic plan. Involved in family engagement and living tree to be deeper family involvement engagement.

Becky - within DPI internal team working on family engagement and bring up that we don't have a common definition and pushing subcommittee to do this. Preschool development grant - there are focus groups. Thurs, parent with child that is birth to 5 join focus groups and give thoughts and opinions and want feedback. Working more with the Health Dept and others. 21st century portfolio, before and after school space - trying to get more engagement with 3 to 5.

Kelli - Community meetings on 1915i Medicaid State Plan Amendment. Bismarck was done on Monday; yesterday Fargo; today is Grand Forks, tomorrow Minot and Oct 1 Dickinson. Potential services: respite. educational support, transition to adulthood supports, non-medical transportation, etc. Hearing directly from communities is important. Contacts are Dawn Pearson and Bianca

Bell. Kelli will forward email on information regarding the amendment.

Jill - Feedback from ID Coordinators - current Right Track contracts are coming to an end. They run Oct 1 to Sept 30. Kudos to state office and we appreciate that they are out so early. Pre-service connections - internships from various professions - many are getting a variety of different disciplines. OT PT Nurse Speech pathologist, special educator and social worker at her program. So we are getting the word out. Another thing - SSIP - developed a lot of strategies and guidance. Work groups from the SSIP has given them opportunity on procedures and professional development. They feel more connected, being able to participate and share processes that are strengthening early intervention across the state.

Anne Carlsen Center - holds infant development programs and doing restructuring but doesn't affect services. Experienced Parent - Misty, Pathfinders, is meeting with Infant Development providers, which came from this group. She was in Dickinson in August and it was helpful and brained stormed some things to take across the state. Designer Gene Walk is this Sat.

Jodi - Children with disabilities buy in program as of July 1st is 250% of federal poverty level. Healthy Steps going from managed care to BCBS so they will be Medicaid children of Jan 2021. They will get Medicaid benefit instead of healthy steps. Can we invite Michelle G to have on the agenda and hear from this group about concerns? As Jodi is a rep., she can take this request to Michelle. Have Michelle present to DDPM and early intervention on how parents can access and utilize this.

Chris - Last month had annual Walk for Apraxia -raised \$13,000. Goes to iPads and assistive tech and therapy

for kids with apraxia. Bismarck only district that has only early intervention the pre-k housed within school district and helps in transitioning kids.

Matt - Experienced Parent is up and running in Williston - quite a few parents and getting referrals. Chatter Pediatric Therapy added 2 speech therapists and got through 100 names on the waiting list. Chatter won best local business award.

Graham is in 1st grade and got invited to first party classmate's birthday party.

Moe - June 14, Family Leadership and taking 25/30 parents, provide hotel, meals and reimbursed for travel. Come and learn about services systems federally to local, talk a lot about Medicaid, networking, and lots of resources. Looking to hire 2 FTEs on the western side of the state, care coordination with mental health with Prairie St. John for pediatric mental health. Next week Wed is luncheon for littles.

Mary - nothing

Sarah - finalizing an invite families to Halloween get together. Involvement with Family Voices for the Power Up Conference in Bismarck.

TOPIC: ELECTIONS

Need to elect a chair and vice chair.

Sarah distributed a draft membership list for review.

Sarah will work with whoever is elected in leading the meeting tomorrow.

Nominations for Chair - Jill S.

A motion was made by Shannon Grave and seconded by Chris Pieske that the ICC elect Jill Staudinger as chair of the ICC. Motion carried.

Nominations for Vice Chair - Missi Baranko, Matt Nelson. Matt Nelson is the new Vice Chair.

Michelle Ragan is in the provider position.

TOPIC: FAMILY SURVEY 2019

Sent out 1,567 and 648 were returned. Did we have a change in our quality? How did it go? Jill said it took time as they had to manually track every survey. It went seamlessly. Took time to track but not overwhelming. Each early interventionist had a list to take out to. DDPM - PEIPS taking into home and have a connection with families and feel this is why we got so many back.

Members like that is was handed out.

This was not a satisfaction survey.

What is the integrity and how to prove we are perfect?

Other states are also questioning the accuracy of the surveys.

Continue with the methodology for next year. Discuss this again in December and finalize process for next year's distribution.

Have thrown out an online version and do we want to pursue. Moe invited Shantelle to be a part of the family survey subcommittee and have a telephone call to discuss.

TOPIC: INDICATOR 2

Haven't had a chance to start this committee as working on the PDG. Did start a data drill down program.

Start it in the new year.

TOPIC: ATTORNEY GENERAL

Sarah hasn't made contact and did before last meeting but didn't hear back from them.

TOPIC: REVIEW STANDARD OPERATING PROCEDURES

Motion from last meeting that there would be advocacy around compensation dollars to add an honorarium for

parents. This Council is Governor appointed and can dollars be used from the Governor Office's and they haven't called back. Sarah will update Jill before next meeting. Reviewed the budget last time, discussion on honorarium and dollars used for ICC. We used \$6,600 dollars and not sure how.

Check reimbursements from March and June. Look at utilizing zoom, skype, etc. for the next year. Shannon has zoom pro and would share her link to host an ICC meeting.

TOPIC: NEXT YEAR'S MEETING DATES

March 26, 2020 -- 9 to 4 - video conferencing
June 18, 2020 -- 9 to 4 - in person
September 10/11, 17/18, 24/25, 2020 -- 9 to 5 - in person
December 17, 2020 -- 9 to 4 - video conferencing
January 21, 2021 -- 9 to 4 - video conferencing

Colette will schedule and send invites to members.

TOPIC: REVIEW ELIGIBILITY CRITERIA

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High risk eligibility list.
Special Health Services Division Director, Medical Director and committee members met several times to categorize the example conditions by organ system. Keep complications of pre-maturity was recommendation of committee.
Made changes based on recommendations of subcommittee. Kim is attempting to clarify "History of gestational and early developmental events suggestive of biological insults", since this was on the original list. If clarification is received, this will be forwarded to Jackie.

What constitutes an informed clinical opinion, Jackie is checking on this. This would be a 4th category. Recommendations, suggestions, and changes are still being taken.

People wanted more guidance on informed clinical opinion.

Would also like input from Behavioral Health.

Not a lot of diagnosis at the age of 3 in the Behavioral Health realm.

Infant Development does the assessments - have at least 2 different disciplines and include parent report.

Need to clarify some of the diagnoses. It was stated that some of the diagnoses are not correct.

Is there a list of the approved tools that programs can use and send to members?

Family counseling is part of early intervention services and not utilized, which includes a therapist and not utilized across the nation.

Committee feel with recommendations, is there any other things to happen with list for DHS to consider?

Go to Behavioral Health Division for any recommendations - do they see anything missing.

Does the list need a DSM V scrub?

Children in foster care or homeless - is this a high risk condition and this is medical focus based on health diagnosis and admin code doesn't say it has to be health diagnosis.

Recognize the difference between high risk and at risk.

Meets definition of at risk prevention dollars for child and family is there federal dollars for families - could be title IV-E prevention dollars. Intent of family first dollars keep out of residential placement and prevent kids from entering the foster system.

Future topic to be high risk vs. at risk and accessing additional funding for families/kids in the future.

Kelly take back for #11 for Behavioral Health Division and Kim will update and forward to the Behavioral

Health Division for additional input, as recommended by the Council.

For the purpose of this list, we need a diagnosis. #18 - change DDCM to DDPM.

#15 - Alcohol related neurology disorder
Kelli will bring input from the Behavioral Health Division to the next meeting

TOPIC: RFP AND SCOPE OF SERVICE FOR EXPERIENCED PARENT CONTRACT

Jackie received some data from Pathfinder to share. 2nd quarter 2019 - 79 direct service contacts - in-person, phone call. There were 35 individuals families served.

3880 minutes provided through those contacts.

The 35 families served region wide across the state - added Region 1 April/May/June but don't have the most recent.

It is lumped together and not big enough to spread out. Of the 79 visits, 35 families were served.

Two questions - how many families in total has experienced parent program supported and using what dollar amount.

From budget we see what DHS has paid but not aligned with direct services.

Worried about the parents not getting served.

Sarah knows she is serving over 100 families, want it to be available to all parents, over lunch went to BECEP and said send me your families.

Develop RFP concerns with consistency and uniformity across the state.

Mary, Region VI needed help, didn't know about this but there wasn't anyone there to help.

Moe serving 35 families over 18 hours a week. Family Voices they get calls when parents don't get a call

back from Pathfinder. On the western side of state they go to Sarah.

To move forward we need some data points. The contract is only going for one year. Parents testified for some of the money, if we don't see the fruits of the labor, it is hard to support and keep going up and saying it is important when services are not being delivered. Had direct connection with staff and DD program staff. Model works best is having a parent embedded in the provider.

Can the provider support this with any money from their organization also?

Other ways to structure, let's make recommendations to the state to explore, let's be more productive.

If we embed, do we open to every single provider, we should at least ask.

Pathfinder has made a data system and can they produce quantitate data.

What does the vision of experienced parent look like and how to do that?

Always having parent perspective present - I think this is missing now.

They have discussed the challenges of finding staffing. Have 4 experienced parents covering the state - Jamestown covers Devils Lake; Dickinson covers Dickinson and Bismarck; and Williston covers Williston and Minot.

Get parents into early intervention

How do we provide recommendations to Pathfinder?

What are other funding sources to make it a good part time job for parents?

Can Jill ask other Infant Development providers if there is an opportunity to embed with experienced parent - do they have funding, space, supporting half time, etc.

Direction from state office and say this is what we expect you to do.

Used data from Bismarck and Dickinson to develop the Fargo program.

Matching funds to be made available, instead of a single contract. Model where DHS has matching funds to offer in each region to hire a parent to do this job and DHS will give you this much money.

There was HSC choosing not to take money.

Challenge is the partnership piece of sharing information.

We have talked about the ICC having some overall supervision.

Tackle it like home visitors being unified.

Treat as a professional position and there are requirements.

Matt appreciates hearing solutions or suggestions; but sees the amount of money and people serving and it doesn't make sense. What are they spending all of this money on?

This is not a Part C requirement.

If you gave the \$260,000 to a region to hire someone but they had to match it, would they do it?

Justification of continued program when you don't know what the data is.

What does the future look like, can't do what we want to do when we put out the RFP?

RFP had conditions and move to a provider held, I worry about the oversight piece.

How do we create quantitative data for the future?

Can get the qualitative data from the troops.

We can work on a data sharing agreement, depending upon what we want to do.

Eliminations of who can be an experienced parent - mentoring experienced parent had been involved with early intervention for years and kids older than cut off age and the history and mentorship was gone.

Also not having someone employed by a provider.

Going back to regional programs and needing to track data.

Some of us to look at data to see what we are looking for? What are the expectations? We are disgruntled about 35 families and the dollar amounts.

Provide matching funds to a provider but share data.

What trainings does Pathfinder provide?

Send experienced parents to the family leadership training institute and all everything is paid for and learn a lot.

State offer partial funding to hire experienced parent.

Share data

Pathfinder hub to supplement training

We would have to procure as we can't change in mid-year.

Access to technology, office space, etc., just like any other position you would hire.

Don't put too many controls on it.

Can the distribution be even, provider matches, etc?

Believe there is equal amount of hours available to Experienced Parents.

Is this a conversation Jill can have with Infant Development Providers, yes? What could they give to the budget part of providing this service?

Work on a survey and want fiscal person and executive director involved - what do you like, how much can you put forward, office space, technology, etc.

Provider - when you have experienced parent in the program, it is easier.

We need some accountability on the end piece also.

Experienced parent does not carry own liability piece, printing and computers are a must.

Next steps:

Put together a survey - Tina and Jill. To include: what is working well, what are you willing to change, willing to put money towards employment insurance tools liability insurance, etc.

Would like experienced parents to have leadership experience - being mentored by Roxane and Missi. In the survey - What does oversight look like and make sure we are creating consistencies across the state. Can we get the number of families served - Jackie will get this information. Can we isolate where they are being served. Ex: 60 families and how many come from each region/town/city. Sarah lists the city and categorical disability. General categories of what is being offered. Data is for accountability and advocating in the future.

TOPIC: ICC MEMBER SUGGESTED AGENDA ITEMS

TOPIC: GREENWAY STRATEGIES: PRESCHOOL DEVELOPMENT GRANT NEEDS ASSESSMENT

Share information that was collected and then have discussion.

Methodology for needs assessment -

- Existing data and requests

- Survey of early care and education providers

- Survey of early intervention service providers

- Interviews with parents

- Interviews with key informants

Survey Methodology

- Online surveys in the field sept 3/13/2019

- Survey of early care education providers

- Survey of early intervention service providers

Shared the key informants that were interviewed

Birth-5 population

64,520 - birth to 5

At risk of developmental delay is 2,715

Graphs of race/ethnicity - young children in state have a more diverse population than the adult population.

Nonwhite race group in 0-4 is growing.

Take aways on population - limited data on dual language learners, homeless group; children birth to 5 and all parents working represent greater population in the less rural areas; racial and ethnics diversity is increasing for children birth to 5.

Capacity:

Showed program types and the number of children served. Net increase for every group but group and home had a big drop.

All license provider - 25% are open before 7am and much lower after 6pm and weekends.

18% of head start children identified with special needs.

70% of providers have had to turn away families in the last year.

Infant and toddler are the highest areas that they haven't been able to fill.

52 providers indicated that they had request to enroll infants that can't be filled because of available space.

44 providers indicated that they have request for toddler but couldn't enroll.

21% providers indicated that families withdrew a child due to behavior or health issues within the last 12 months.

Capacity conclusion:

Heard and gathered data for more capacity in general

Needs for more capacity for infants and special needs

Need for more flexible hours

Lack of child care perceived as a barrier to workforce development

Share:

Question 1:

Reflects knowledge and experience information missing relates to pop of people we are supporting, children with special health care needs. See more information on children with disabilities. Percentage of families turned away because of medical/behavior needs. What does the withdrawal mean? Expulsion rate is missing. What are the reasons for providers closing?

Data didn't surprise us. Sometimes you can't be picky if you can't afford it.

Slide more clear about birth rates and groups going down and up. Difficulty around women working. Second mortgage to pay for child care. K

Is commerce still giving out grants? Grants can be obtained through Amanda Carlson's office for expansion for serving or are serving children with special needs.

Wait list data needs to get represented. What is the actual percentage of providers that have an actual wait list?

Potential barriers of being turned away because of background race, demographics, can you expand on this?

In-home supports - reflect the statistics if the kids are receiving in home supports.

Barriers to Access:

Cost, affordability,

Majority children receiving financial assistance through childcare assistance are enrolled in centers.

26% of providers indicate one or more families withdrew their children due to financial payment issues.

Lack of services for children with special needs or special health needs: 21% of providers indicated that families withdrew a child due to behavior or health issues within the last 12 months (couldn't ask how many have technically been asked to leave).

Lack of transportation - 16% of providers indicated that families withdrew a child due to transportation to and from their program within the last 12 months. Of those survey 32% offer transportation to and from their program.

Lack of adequate information in terms of a child developing.

Lack of service for students with a home language other than English.

Conclusion:

Financial assistance

Lack of capacity and lack of support for students with special needs.

Lack of transportation.

Parents need greater access to information about early care and education options

There are limited services or children who are dual language learners.

Reponses:

Barriers to accessing financial assistance; dual language learners training to professionals acting in the home; parents needing greater access - to better presenting of the information.

How many qualify for child care assistance and how many actual receive it.

Lack of transportation - can you provide some context with this? Doesn't mean you don't have a car.

Education for parents.

Parents withdrawing from services - wording to be more family friendly.

Quality:

145 programs participating in the regions.
Stakeholders had lots of questions on quality,
identifying quality.

Conclusion:

10% of provider participating in the system in ND.
Those participating majority of program are in step 1
and 2 and majority of children in the lower rated
programs.

Parents have difficulty defining and identifying a
quality program.

Comments:

Cautious of using the words "lower rated".

Challenges of providers

Providers business challenges include regs, high costs
and paperwork.

Conclusion:

Providers having difficulty hiring and maintaining high
quality staff

Providers business manager challenged with paperwork
and regulations.

Challenges in the Delivery System:

Conclusion

Multiple layers and agencies hinder efficient delivery
of services.

There is not a one stop shop for parent to understand
and locate childcare.

System of delivery is a barrier to providers entering
the market.

Pending sunset of the Waiver or state special
background check is a threat to the current childcare
capacity.

Comments:

Background check - overview slide of differences for childcare providers vs teachers,

How council can be supportive, impacts the work that we do, and the end goal.

Next Steps:

Responsible for the needs assessments and 2nd part is the strategic plan - what should we do about it. Working on the methodology for engagement for the strategic plan. The ICC meeting is towards the end of our strategic planning and could we get your input virtually. In December, share the draft of the strategic plan and have you respond to that.

TOPIC: STANDING NDICC AGENDA ITEMS

Part C Budget Report

Pay Point & Administrative Expenditures

Detail for expenditures through 6/30 was shared. Started spending FFY 18 in July 18 and FFY 19 in July 19. 49 kids not using Medicaid.

Tina met with Caprice Knapp, new DHS Medical Director, and brought this up and looking for a possible solution.

Committee Reports

EI Budget Committee

No report.

Ex Committee

Reviewed the agenda.

EI Services Committee

Becky talked about this earlier.

SSIP Committee

Work that Jackie showed us representing that committee.

Family Survey Committee

Discussed earlier.

State Systems Improvement Plan Update

Roles and responsibilities - 2 versions - 1 checklist type to talk about Roles/Responsibilities across regions to make sure we are being consistent and 1 is more visual from the procedures workgroup. IFSP checklist with 2 versions is also from the procedures workgroup. This checklist is a compilation of what each brought.

PDG supported SPARK Communication trainings in Bismarck, Minot and Fargo. These support the SSIP also.

General Supervision Update

APR closed data collection and will start analysis of the indicator. Table 3 is out with field to review. Jackie will send the presentation to the members on the data table.

Beginning of Oct, timely services and 45 day time line will go out to the regions/field for review and corrections.

This will be posted to the website also.

Letter of findings and letter of determination will be out soon. Working OSEP to report on indicator 3 - make sure what and how reporting meets OSEP needs.

DD Slot Report

5233 slots are assigned.

135 Infant Development

A slot is tied to Medicaid - have to have Medicaid to be in the waiver. Pending Slots - looking at why the slots are being held for a particular person. Kudos to best practice of showing families what they do and don't need to share on the Medicaid application. Parental income and asset is not looked at when applying for the Waiver, only the child's.

NDICC Membership Updates

Assuming the appointments are made, we have an opening for a parent in Region III. Amy works in Region III but we need her to attend a meeting. Does the Region III parent rep have to be from Devils Lake or another region? Open up Grand Forks, Fargo, and Native American population.

Attendance - Sen Poolman hasn't attended for one year. Sarah will talk to her.

Meredith - contacted Sarah last meeting, so Sarah will talk to her also.

Email corrections of start dates to Sarah and she will visit with Julie.

Pathfinder Report

No report.

Matt - leading by convening. Do this at the December meeting.

Collaborative - early intervention to be a part of all conversations; collaboration between parents and professionals - be some action work where we could see that unfold in an ICC meeting would be great.