South Dakota Supporting Families CoP State Team Meeting

April 1, 2020

Present:

Family Members & Self-Advocates	Family Member w/Professional Role	State Agency Representatives	Public/Private Partners
• Valerie Tieszen, • Dawn Kirchner, Yankton • Brenda Smith*, Sioux Falls • Cindy Whitmore, Rapid City • Nick Anderson, Yankton • Elaine Roberts*, Sioux Falls • Kayla Duncan, Winner • Tania Kostal, Tyndall •	• Teri Bukowski*, parent/Benchmark • Carrie Geppert*, parent/DHS-DDD • Deanna Wollman*, sibling/South Dakota Developmental Center (SDDC) • Letty Thelen, parent/Center for Disabilities	• Arlene Poncelet, DD Council • Julie Hand*, DHS Division of Developmental Disabilities (DDD) • Kimberly Percival*, DHS-DDD • Bianca Villapudua, DHS-DDD • Kelli Anderson, DHS-DDD • Julie Johnson-Dresbach, DHS-DDD • Dona Deal, DHS-DDD • Barb Hemmelman, DHS-DDD • Jenna Hieb, DHS-DDD • Stacy (?), SDDC • Whitney Brunner, Dept. of Health Community Health Services • Barb Wetrosky*, DHS-Long Term Services & Supports (LTSS) • Donna Fischer, DHS-LTSS Ombudsman Program • Melissa Flor*, Dept. of Education, Educational Services & Supports	• KD Munson*, RHD Case Management • Theresa Marzahn, RHD Case Management • Carla Miller, SD Parent Connection • Kristi Patton*, Ability Building Services • Jan Johnson, Family Support Coordinator (BHSSC) • Mennite (??), Family Support Coordinator • Tacey Dunwoody, Benchmark Case Management • Becky Israelson, Family Support Coordinator (BHSSC) • Rose Moehring, Center for Disabilities • Nikki Kavanaugh, Family Support Coordinator • Jill Fischer, Family Support Coordinator • Brian Poelstra, Disability Rights SD

◎ Answer Using the Chat box, complete this sentence: *"I'm on the SD State Team for Supporting Families because…"*

★ Dawn Kirchner - Yankton, My daughter has Autism and we work with ABS here in Yankton. I am also president of our local A-Team. Kristi Patton thought this would be a good thing for me to get connected with

★ Brenda Smith: I want families to be able to envision of positive future for their family member and I want families, the whole family, to be supported as they face extraordinary responsibilities throughout their family members' life.

★ Melissa Flor: Pierre, try to help provide a good transition from education to other agencies

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★Arlene Poncelet: supporting individuals and families is important to the SD Council on DD and learning how to do that better

★Jill Fischer: I am a parent and also a family support coordinator in SE South Dakota and i want to be able to learn more how to support my families and also for myself.

★Jenna Hieb: Chamberlain, SD - Occupational Therapist, prior Family Support Coordinator, and brand new employed with State of SD DDD Intervention and Support Specialist. Always eager to learn more!

★Nikki Kavanagh: here to learn better how to support families that I work with.

★Rose Moehring: I am on the SD State Team to learn how the Center for Disabilities might best support families.

★Dona Deal: While working with referrals and connecting people with supports and services within their home communities, it is important to do this work within the philosophy of CoP.

★Nick Anderson: I'm on the SD state Team for Supporting Families because my brother recieves services through ABS in Yankton.

★Elaine Roberts: Sioux Falls I think we have opportunity to make a difference through this prcess and way of thinking.

★Donna Fischer: I am from Murdo SD, I work for the Division of Long Term Services and Supports within the Department of Human Services. I run the Long Term Care Ombudsman Program for the State of SD. We work with all individuals living in nursing homes, assisted living centers and community living homes across the state.

★Teri Bukowski: My work with the participants and families in our Family Support Program as well as I am a parent who has witnessed the success of using the tools of the CtLC.

★Tania Kostal: This is Tania Kostal parent from Tyndall, SD. This is my first time here and just observing.

★Julie Johnson-Dresbach: Sioux Falls. I am on the state team because I believe we need to honor and recognize and promote and facilitate the support between family members and the interdependence between us all.

★Bianca Villapudua: DDD Pierre. I am on the state team because I believe it is important to support not only individuals but the family as a whole.

Review of CoP Purpose and Core Belief – see attached slides

Roles:

- Timekeeper – Elaine

- Recorder – Bianca

- PowerPoint presentation – Julie H/Kim P

Goal 1: Self-Advocate & Family Networks

- *Poll Question: What can provider agencies and other organizations do to better connect with families and self-advocates?*
  - Kayla Duncan- self-advocate- Kayla states that CCI, Community Connections CSP, is helping her.
  - One family member stated she has to go online and find resources, which can be very difficult.
  - See families as the experts.

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- o Be open to ideas that might be different than "what we've always done"
- o Get to know people and families and understand the impact of disability on a family.
- o Be proactive in providing information to families. If you find something you think will help, share it. Many times, families that come to the autism support group do not know what they're looking for or what might help. I bring a ton of information to pass around and share and explain what things are and I find that seems to be helpful.
- o Have agencies really push, encourage, and help self-advocates. Especially those with no or limited family contact.
- o Encourage training to staff members as well as families
- o Information provided in multiple formats, not just written brochures or websites. Physically show up to events/ meetings that families are already at. Having person to person conversations
- o Offer a variety of ways to connect with the people you serve.

Goal 2: Private and Public Partnerships

- *Discussion Question: How can I, as a CoP member, help expand public/private partnerships?*
  - o Needing partnerships with long term services and supports, not just those in school systems. We need to be looking at all aspects of life, we seem to focus on the younger school age instead of all life transitions.
  - o How do we expose people to framework without formal presentation?
  - o You may not need to do a formal presentation in order to share the framework and all it can do. Sometimes just an impromptu conversation can happen.

Goal 3: Supporting Families as a Priority within DDD

- *Poll Question: When you hear policy what do you think of?*
  - o Complicated
  - o Rules x 2
  - o Standard practices and priorities
  - o Regulations
  - o Legislature
  - o Guidelines
  - o How organization are going to do their business!
  - o Rules and standards
  - o Guidelines not always black and white lots of gray at times and funding is limited at times
- *Poll Question: In order to create policy, we need partners and feedback, do families feel that they can provide feedback and be heard? How do families get their input to organizations and agencies? How do you know that you were heard, even if not all the changes you asked for were made?*
  - o Providing consistent answers
  - o Hearing "we've never done that before"
  - o Policies that actually add stress and burden families
  - o Not knowing where to go for help

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- Policies that don't offer room for Individual needs
- A people first understanding of the policy which affects how supports are available
- Too many acronyms. And ditto to all the above.
- Once again not being able to do things differently
- Feedback not especially valued. Ran up against a big wall when trying to partner with provider
- Agencies and organizations need to look at the needs of individuals and families and if those needs that don't fit with in policy - don't just tell families no - organizations and agencies must reflect on the policies and ask - about those needs - do we need to change policy. etc.
- Agencies must get uniformed questionnaires, so we are not filling out the same form 10 different times

System Needs vs. Human Needs

- System requirements may make people feel more exhausted, but how can we meet human needs and meet system requirements.
  - Focus groups around the state and opportunities to give the DDD feedback, feedback is very important and valued.
  - The Division is trying to get more families involved in the system and their needs. Trying to balance.
  - Division is wanting to know about families front door interactions that they have had with the system.
  - Human needs side more accessible and not so burdensome
  - Would like check in and monitoring more meaningful, rather than just a check list.

Online Good Life Groups:

- Goal is to connect with families with similar life experiences, introduce CtLC framework and looking at the integrated star to look at different types of support
- Recent group held over 3 weeks. 6-7 people signed up and met up online over the lunch hour
- If you are interested email Brenda Smith – any preference in time of day, day of week, etc. will help inform the next group (limit to 10 people)

COVID-19 pandemic: Applying CtLC to adjust (see examples)

- This is a difficult time for all, but particularly for people with disabilities and their families.
  - Confusion with the wording of social distancing, which is physical distancing, explaining that to families. Currently research being conducted in physical versus social distancing. South Dakota is ahead of the game by using the terminology physical.
  - Using technology and keeping connected with social distancing occuring
  - Using the Trajectory to re-establish or adjust the vision of a "good life" for working, teaching and generally STAYING home.
  - Using the Integrated Support Star to consider how to stay connected to others, maximize technology, tap into community resources to supplement eligibility based supports.
  - Good to have a one-page profile completed in case families get separated
- Comments about examples:
  - This is awesome Brenda!
  - This helps me understand the Trajectory. I like his comment on What he doesn't want is Drama. I have that on Kayla's as well. How can we help them stay out of the Drama?

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- Nice work Derek and Brenda and thanks for sharing your real life example!

Upcoming Events:

- CtLC webinar series are being held by life domains
  - January-All and Universal Strategies – recording available soon!
  - March- Rescheduled to May 20th- Safety and Security
  - May- Daily Life and Employment
  - Being held throuhghout the year and into 2021.
- Implementation and Practice Innovation Workgroup:April 2nd, 2020
- Cultural and Language Competency: Is becoming a popular topic. This discusses how people think about disability and culture, even aging parents. May 12th currently scheduled
- Rescheduling in person meeting to *possibly* June 3rd, 2020. Want families, self-advocates, etc. to attend, not just providers and professionals
- Will continue to host monthly state team meetings

Updates:

- Adding CoP Overview to DDD homepage as well as additional detail regarding the role of SD CoP State Team
- Adding Supporting Families page updates to DDD web page
- CoP is currently prioritizing goals and showing accomplishments. Trying to get active family involvement
- Annual CoP meeting in Kansas City, MO originally scheduled for April 28th. This will be conducted over the course of several meetings will be held remotely over the course of several meetings
- Also, the Charting the LifeCourse Showcase has been postponed to a later date due to COVID-19. this date has not been determined yet,.
- If you have questions or would like additional information about the SD CoP State Team or CtLC, reach out to Ambassadors in order to get information (see slide)
- Innovations Work groups meetings are available through our CoP membership and open to any team members.

  - A schedule of Innovation Workgroups is also included with the minutes – topics for the Workgroups include:

    - Family and Self Advocate Engagement
    - System Design and Quality
    - Implementation and Practice
    - Cultural and Linguistic Competency