



SUPPORTING FAMILIES

of individuals with intellectual & developmental disabilities
THE NATIONAL COMMUNITY OF PRACTICE • A COLLABORATION BETWEEN NASDDDS AND UMKC IHD, UCEDD

SOUTH DAKOTA STATE TEAM

South Dakota Supporting Families CoP State Team Meeting DRAFT #1

August 5, 2020

Jessica Lamb facilitate the opening round with the following present:

Family Members	Family Members w/Professional Roles	State Agency Representatives	Public/Private Partnerships
Brenda Smith Elaine Roberts Sara Valle	Tim Reinbold, parent/VR Councilor Teri Bukowski, parent/Benchmark Carrie Geppert, parent/DHS/DDD Deanna Wollman, sibling/SDDC Brian Poelstra, parent/DRSD Letty Thelen, parent/Center for Disabilities Jessica Lamb, parent/Augie Access Tania Kostel, parent/Family Support	Arlene Poncelet, DD Council Julie Hand, DHS/DDD Kimberly Percival, DHS/DDD Julie Johnson-Dresbach, DHS/DDD Dona Deal, DHS/DDD Barb Wetrosky, DHS/LTSS Linda Turner, DOE Special Ed Sara Carter, DOE Part C Melissa Flor, DOE Jodi Berscheid, DOE Kayla Mitteness, DHS/DDD	KD Munson, RHD Carla Miller, SD Parent Connection Kristi Patton, Ability Building Services. Teresa Marzahn, RHD Nick Anderson, Therap Tacey Dunwoody, Benchmark Becky Israelson, Family Support

Review of CoP Purpose and Core Belief – Kristi Patton reviewed the core belief of CtLC and the purpose of the Supporting Families CoP as well as the meeting agreements.

Roles:

- Timekeeper – Arlene
- Recorder – Elaine
- PowerPoint presentation –

Carrie Geppert presented information on **Guardianship and Alternatives to Guardianship Options**. She indicated that she is not an attorney and that those interested in this should consult an attorney.

- **Transfer of Rights** needs to be considered at various stages of life—age 18, change in health/mental, and aging
- **Supported Decision Making (SDM)** is a fancy name for what we all do everyday –ask people we trust for help in making decisions.

Sometimes it seems easier to just decide for someone, but by allowing them to make their own decisions and mistakes, we teach self-determination and allow for growth.

- While guardianship takes away rights, a **power of attorney** creates rights.
 - Commonly used in business and in estate planning
 - One competent person (the *principal*) gives another (the *attorney-in-fact or agent*) the right to act on their behalf in certain situations.
 - Healthcare Decisions –provide copies to providers



- Financial Management –e.g. banking, bills, cell phone plans
- A limited **guardianship/conservatorship** avoids a guardianship that is overly broad and restricts rights the individual is capable of exercising fully to some degree.
 - Can be expressly limited in TIME or in SCOPE - ask the court to order protection only for what's needed.
 - The protected person retains all rights that have not been granted to the guardian/conservator.
- **Full Guardianship and Conservatorship**
 - Prevents Transfer of Rights, if completed before 18th birthday
 - Traditionally a default option, but also the most restrictive.
- **Guardianship** is relationship in which one or more individuals (guardians/conservators) make decisions on behalf of another individual (protected person).
 - **Guardians** make decisions about everyday life (e.g. healthcare, food, living, associations, work, etc.)
 - **Conservators** make decisions about finances (e.g. spending money, savings, real property ownership, personal property management, etc.)
- **CtLC tool** for exploring decision making support and the Integrated Support Star were shared. Fillable documents will be included with the notes.

Breakout Discussion and summary: What are the areas of need surrounding Guardianship and/or Alternatives to Guardianship for families?

- Inconsistent information from school districts across the state
- Systemic plan for training across areas
- Families fear not being invited to IEP meeting if guardianship is not established prior to age 18
- Earlier information for families (allows time to help build the skills for decision making)
- Early childhood life experience booklet available to assist families
- More information around aging
- More information about healthcare directives
- 5 Wishes! It's a great resource to walk through end of life planning, advance directives, etc.

Breakout Discussion and summary: Based on the identified needs, what & how can the SD CoP State Team provide resources to families?

- Coordinate a “show & tell” by each agency/organization that deals with this so we can identify missing information
- Provide information on one page with links to various groups
- Create a short video for families that addressed these issues available 24/7
- Ensure information is reader friendly and consistent
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Kim: A Guardianship Work Group is being formed that requires a commitment of one hour per month for 4-6 months. If interested in serving, please contact:

Kimberly Percival Kimberly.Percival@state.sd.us 605-773-3438 or **Brooke Nelson** Brooke.Nelson@state.sd.us 605-773-3438



CoP Goals/Barriers/Discussion Summary -Kim

- **CoP Goals**
 - Self-advocate and family outreach
 - Initiate and/or further develop relationships with key state and local partners
 - DDD systems change
- **Barriers that effect people with disabilities and their families**
 - Mental Health
 - Transition Age Services
 - Funding

Summary of barriers/challenges

- Accessible transportation
- Difficulty finding information/not knowing where to find info/resources
- Mental health crisis supports, understanding the system
- Crisis Services
- Inflexible funding
- Access to services/supports in rural areas
- Medical supports in home and providers and funding
- Dissolving active guardianship
- Work experiences for school age - depends on the district for project skills or when it is offered, etc.
- Lack of available programs to provide assistance to individuals. Due to no program or due to geographical region
- Eligibility requirements and documentation
- Consistent information among agencies
- Enough staff to work in the field to support individuals, longevity of staffing
- Elderly there seems to be a stress on caring for the caregiver. There is a different attitude toward caregivers when you have a child with a disability
- Parents wanting parent mentors/leaders to help navigate disability land
- Too many confusing hoops to jump through to get any help.
- Young people that have graduated and falling in the gap between age 18 and 21 and not being able to access as many supports as they might need.
- How to sustain knowledge with a field that constantly changing and how to share the updated information across systems.

Breakout Summary What solutions need to be created?

- Pull all the resources together—we have all of the various groups represented in the CoP
- Have consistent and accessible information in a variety of formats
- Eliminate duplication of services (sometimes families...and providers get the same information in several different emails)
- Look at the system(s) as a whole and provide broad training



Brenda shared:

- The availability of an online Good Life Group to learn more about the tools and CtLC ways of thinking. A short-term group might be for families, teachers, or others who want to learn more about CtLC.
- The upcoming online sessions about the various domains: September 23rd – Community Living, November 18th - Social & Spirituality, January 13th, 2021 - Healthy Living. You need to register for these sessions to get the link and reminder
- All previous recorded webinars can be found on the DHS website under Supporting Families Community of Practice

Kim announced that Julie Mendelson, Shannon Torres Negrón, Patty Smith and Tana Buresch are taking the Ambassador series

Next meeting is October 7, 2020