

Supporting Families Community of Practice Evaluation

Redefining Success: South Dakota's Story

“The concept of person-centered thinking has, for years, been ingrained in our minds as paying attention to the person with a disability, who they are, and how to best support them. Bringing families to the table has brought new perspective to the idea of person-centered practices. Families are fierce advocates- they help us better understand the perspectives of those we aim to serve each day. Reframing our efforts to better meet the needs of South Dakotans-as defined by them- has helped us shine a light on our tendency as professionals to rely only on our expertise and frame of reference when making decisions. How can we make positive change if we don't first ask what change is needed?” –Julie Hand

Overview

In 2012 the Administration for Community Living (ACL) funded the development of a National Community of Practice for Supporting Families (CoP) to help state agencies and stakeholders, such as families, make systemic changes that positively impacts individuals with intellectual and developmental disabilities (I/DD) and their families. The CoP is driven by a set of principles that comprise the Charting the LifeCourse (CtLC) framework designed by and for families through the University of Missouri-Kansas City (UMKC)-Institute for Human Development. The core belief of the CtLC framework is that all people have the right to live, love, work, play and pursue their life aspirations in their community.

In 2017, ACL funded an evaluation of the CoP to identify measurable outcomes achieved by the sixteen participating states. The evaluation uses five categories to evaluate the benefits of the CoP and CtLC: sharing information and creating partnerships, increasing knowledge, changing practice, improving performance, and redefining success. This document highlights themes observed across states that relate to the fifth category: *redefining success*.

Category Five Activities: Redefining Success

- Measuring outcomes in new ways because of the CoP
- Changes in goals/strategies/system operations because of the CoP

Themes across States

Several themes regarding *redefining success* emerged across all sixteen states participating in the evaluation. States highlighted how changes in knowledge capital and practices that occurred in previous categories led to new ways of measuring success. Success, as cited by the states, refers to advancing new goals, strategies, and system operations resulting from the CoP. Some states aligned outcomes for their state developmental disabilities (DD) agency with the CtLC framework and embedded it into scopes of work, strategic plans, and evaluation methods. States also noted significant changes to their DD agency's approach to work, which looks at both the families and individuals. With these changes in goals and strategies, some states are focusing on new ways of measuring outcomes. This category takes into consideration the varying degrees of states' sustainability and their revised use of the CtLC framework.

South Dakota's Story

Julie Hand, the Assistant Director of South Dakota's Division of Developmental Disabilities, illustrates how South Dakota's CoP reframed its goals and approach to include family members in decision-making and planning processes. She notes that having their voices present in the CoP helps develop effective strategies moving forward.



Julie Hand is the CoP facilitator for South Dakota. In 2017, Julie, along with several state team and family members involved in the CoP, attended the CtLC Showcase. Afterward, the state team began to debrief the event, brainstorming ways to incorporate what they learned into practice. Lynn Rick, a family member in attendance spoke up and abruptly asked why she was there if the state team intended to develop strategies without consulting family members. This interaction was a turning point for South Dakota; they needed to think of better ways to involve families.

Previously, South Dakota's stakeholder groups largely included professionals. Engaging families in the process of developing CoP goals became Julie's main objective. Through facilitated discussion with a select group of family members, Julie ultimately decided to hold family listening sessions across the state. A family member facilitated each of the ten listening sessions, which consisted of open conversations. The meetings provided families the opportunity to voice their concerns, and provide direction for the state team. Overall, the exercise helped the state team gain a deeper understanding of what families actually need, and how the CoP could support them.

South Dakota made several other adjustments to its approach. They created "Good Life Groups", where families could learn about the CtLC tools and connect with others. The CoP is planning to host these on a regular basis in the coming years. The state has made efforts in other areas, including hosting Skype meetings, presenting at family conferences, and engaging in community events. The CoP also asked families to update the DD agency's brochures to help create a more comprehensive resource to outline available services and supports. Another major shift in strategy of South Dakota's CoP is to involve families at the beginning stages of policy development. This places their needs at the forefront of change.

In summary, South Dakota's CoP took great strides to incorporate the families' perspective into its goals and strategies. They identified areas for improvement based on feedback from families. This includes creating systemic change, engaging tribal communities, organizing front door services, and encouraging staff to utilize CtLC tools to frame their work.