



Community of Practice Annual Meeting Summary 2021

May 26 and May 27, 2021 – 1pm to 4pm (Central)

Community of Practice Annual Meeting Day 1:

Welcome, Introductions and Purpose of the Meeting

The National Community of Practice for Supporting Families (CoP)– a partnership between the National Association for State Directors of Developmental Disabilities Services and the University of Missouri-Kansas City Institute for Human Development, UCEDD – hosted the 2021 Annual Meeting for member states to:

- Share learning between CoP states, and as a full CoP, to both:
 - Celebrate and highlight the work of the states over the past year, ensuring states can hear concrete information, updates, and ideas from one another
 - Identify potential "next steps" for states individually and the CoP collectively as part of the "supporting families movement"
- Prepare for the year ahead by:
 - Engaging in specific, focused conversation around actionable strategies that "weave in the principles of supporting families in both grassroots and system work to support state priorities"
 - Discuss state ideas and priorities to help the National Team shape ongoing technical assistance and support

Foundations/Beginnings of Supporting Families - The Past, Present, and Future

Dr. Sheli Reynolds, Assistant Director of the UMKC Institute for Human Development, provided an overview of the history of supporting families, which focused on highlighting and celebrating the successes of the past 10 years in working to support families. It served as a reminder and grounding in the principles of supporting families that were initially established at the 2011 [Wingspread Family Support Summit: Building a National Agenda for Supporting Families with a Member with Intellectual and Developmental Disabilities](#) and concluded by setting the stage for the future, including how these principles evolved, and have impacted policy, practice, and system change.

Sheli outlined the distinct goals for supporting individuals and families, while recognizing that individuals exist within a family system. This aligns with the vision for supporting families, in



which integrated services and supports are structured within the context of the person, family, and community.

Sheli also revisited the original project goal behind the convening of the Community of Practice: To build capacity through a community of practice across and within states to create policies, practices, and systems to better assist and support families that include a member with intellectual developmental disability across the lifespan.

The specific project outcomes of the original grant forming the National Community of Practice for Supporting Families were to develop:

- State and national consensus on a national framework and agenda for improving support for families with members with I/DD
- Enhanced national and state policies, practices, and sustainable systems that result in improved supports to families
- Enhanced capacity of states to replicate and sustain exemplary practices to support families and systems

The Community of Practice has also been shaped by and influenced the development of the Charting the LifeCourse (CtLC) framework. This framework is grounded in the core belief that “all people have the right to live, love, work, play and pursue their life aspirations.” Initiated by the quest to answer the question, “what do families need to know to support their family member with a disability across the lifespan?” the key principles have driven a transformative human-centric movement impacting policies and practices across the country.

An overview of the following Charting the LifeCourse Framework principles, and how CoP member states utilized these principles to enhance policies, practices, and systems for supporting families:

- Focusing on All People: thinking about the populations they serve, as well as those outside their service system. This includes linking to new or underserved populations or connecting with complementary systems like school systems, foster care, or mental health systems, as well as collaboration with community resources.
- Trajectory of Life Experiences Across the Life Span: focusing on the policy and procedural practices that need to happen very early in and throughout the lifespan. This includes linking to supports and systems that specifically contribute to areas across life stages, including early intervention, school, transition years, aging, and overall disability systems.



- **Holistic Focus on Life Domains:** ensuring that all life domains are addressed when creating new policies and procedures to create better life outcomes. This includes health and safety, work, social and spirituality, self-determination, and supported decision making.
- **The Three Buckets of Support:** aligning state procedures to ensure that all “three buckets” are being filled. The buckets are “discovery and navigation”, “connecting and networking”, and “goods and services”.
- **Integrated Supports Star:** integrating and leveraging services and systems change to build out each part of the star with the goal of balancing community and technology supports, relationships and paid supports to improve quality of life.
- **Transformational Policy, Systems, and Community Change:** ensuring that the person and family are driving the system, including elevating their voices in policy change. This includes stakeholders in meaningful roles alongside policymakers in all change.

Breakout Room Questions, Discussion and Sharing

To reflect on the history and growth of the supporting families movement, attendees of the Annual Meeting participated in breakout room discussions and identified the following celebrations:

- The CtLC framework is an historical unifier, creating common language and facilitating partnerships and collaboration with families.
- Using CtLC as a “lens” has helped I/DD systems to view families as critical partners, with a valued role at the table of systems change.
- Strategic systems transformation remains the priority, with a focus on embedding practice and programmatic changes into policy
- Specific system changes that have enhanced supports to families include:
 - Infrastructures to support ongoing outreach and capacity building (such as: regional or local collaboratives)
 - Addition of peer mentoring supports and education for families as reimbursable services (in many states)
 - State system having parents or family members as state employees within the system to help build the change and bridge connections
 - Influencing practices, policies and waivers through having a meaningful seat at the table



- The natural and healthy tension between self-advocates and families is recognized and honored to facilitate supports to the person within the context of their family for a good life for all.

To build on the work so far, the following areas were identified as ongoing priorities for consideration:

- Developing equitable policies, continued learning, and fostering an environment of cultural and linguistic competency to support individuals and families of all cultures and family contexts, including representation of culturally diverse families in advisory or other impactful capacities
- Continued inclusion and support of families in advisory or other impactful capacities
- Expanding the definition of supports to include integrated resources, supports and services that meet discovery and navigation, connection and networking, and goods and service needs
- Similar, plain language resources with a common language among sister agencies within and between states, supporting a consistent “user experience” and enhancing system navigation for families
- Supporting long-term and crisis prevention/response planning
- Working to ease tension between:
 - Traditional segregated day services while moving to community-based services
 - Best practices and what is politically/financially possible in real communities

Overall, the breakout rooms highlighted four (4) key aspects for harnessing the knowledge of where we have been and bringing it into the future work of supporting families:

1. Embedding: not mandating or requiring, but embedding the language, values, and principles into policy, training and engaging
2. Listening: making sure families and self-advocates are heard in leadership roles
3. Partnering: collaborating with key partners, such as the DD Councils, and other systems/sister agencies to support “the all”
4. Quality: focusing on quality, recognizing the substantive changes, and ensuring these changes are continually evaluated for quality using the values and principles of supporting families



Current Context and Celebrations of Supporting Families

Mary Sowers, NASDDDS Executive Director, continued the celebrations, highlighting where the supporting families movement is now and what role the Community of Practice plays in the overarching goal of supporting individuals and families to live their best lives. She specifically shared the important impact of the CoP during the past year.

Mary emphasized the importance of including families in all facets of systems change. By including and leveraging the voices of individuals and families, we can gain a deeper understanding of how supports and services can be influenced by families and improved to better fit the lives of the individuals being supported. In order to integrate families into the system processes, it is crucial to dedicate significant supports and resources to support individuals and families to participate in a meaningful way. This can also help establish relationships and trust, which further the impact of family voices.

The Community of Practices has played a role in truly embedding these changes into state DD agencies. By ensuring these practices are woven into the fabric of the system, these changes become more sustainable, integrated, and long lasting. The influence of the CoP is notable in supported employment work, case manager work, quality improvement, the National Core Indicators, and many other facets within the system. The Community of Practice has also made significant waves with other organizations across the country, which help spread the reach of the supporting families movement.

In conclusion, Mary Sowers thanked the participants for their commitment and innovative thinking. She congratulated their continued partnership, passion, and support to the individuals and families served across the country.

One Slide Challenge: State Celebrations

To close the first day of the annual meeting, states had an opportunity to hear and learn from each other and to highlight and celebrate their significant, meaningful, and unique accomplishments. This portion of the meeting showed the impressive changes and activities of member states.

The state videos are included on the state's profile on the Community of Practice website [here](#).

The conference concluded by positioning CoP teams to come together on Day 2 to strategize how to continue to build on the celebrations and address ideas for moving forward.



Community of Practice Annual Meeting Day 2:

Welcome, Introductions and Purpose of the Meeting

The National Community of Practice for Supporting Families National Team hosted the second day of the 2021 Annual Meeting for member states to continue:

- Shared learning between CoP states, and as a full CoP, to both:
 - Celebrate and highlight the work of the states over the past year
 - Ensure states gain concrete information, updates, and ideas from one another
- Engaging in specific, focused conversation around actionable strategies that "weave in the principles of supporting families in both grassroots and system work to support state priorities"
- Discussing state ideas and priorities to help the National Team shape ongoing technical assistance and support
- Preparing for the year ahead by:
 - Engaging in specific, focused conversation around actionable strategies that "weave in the principles of supporting families in both grassroots and system work to support state priorities"
 - Discuss state ideas and priorities to help the National Team shape ongoing technical assistance and support

Harnessing a Grassroots Movement for System Change: Focusing on Strategies

This portion of the annual meeting was aimed at setting the stage for a discussion around how member states can work within the existing opportunities and initiatives within their state to further the goal and work toward the vision for supporting families:

- Goal: To build capacity, through a community of practice, across and within States to create policies, practices and systems to better assist and support families that include a member with an intellectual and developmental disability across the lifespan.
- Vision: Integrated services and supports are structured within the context of the person, family, and community to avoid isolating the individual by wrapping the services around them

In order to accomplish this vision, grassroots and system efforts work together to maximize the impact and further the ongoing priorities of the state, while at the same time, emphasizing the



importance of both simultaneous grassroots momentum and systemic policy change to create lasting, sustainable transformation.

Annual Meeting participants – representatives from CoP member states – were offered an opportunity to share and learn with one another related to specific resources, tools, and ideas the area of their choice:

Grassroots Strategies: knowledge and practical application of family and self-advocacy engagement, outreach, connections, and leadership at the local and state levels. Specific ideas that were highlighted include:

- To increase opportunities for grassroots collaboration, organizations can bring people to the table of different cultures.
 - o One way to move toward this goal is to revisit hiring practices to ensure they are equitable and that there is an emphasis on hiring people with lived experience.
 - o At the same time, organizations should consider providing training and support for individuals who may be new to the “table” to ensure they can effectively advocate for their needs.
- To maintain momentum, cross-system communication and sharing is essential
 - o Each organization would benefit from assessing their current connections and work to establish and identify new areas for collaboration with the focus on building relationships by connecting people and professionals.
 - o A key aspect of sharing and communication is having an accessible, updated, and central location or website for compiling and distributing resources — including requests for training and information
 - o Another way to approach collaboration and partnership is through providing family networks with grants or other forms of professional support or connecting people with I/DD with technology
- To further support grassroots, there should be an increased emphasis on peer support and mentoring, where self-advocates and family members are included as the leaders/trainers, etc.

System Strategies: state-specific and cross-state strategies on how to develop practical actions that can be applied to priority state systems change. Specific ideas that were highlighted include:



- Involving families in decision making roles as much as possible and gathering feedback and input surrounding policies and practices.
- Ensuring initiatives can be tied or integrated into ongoing projects by grouping together similar efforts that are complementary. This helps build momentum and create buy in by avoiding making it “one more thing” for people to do.
- Combining diversity, equity, and inclusion efforts and initiatives to make them more impactful and identifying areas that overlap with supporting families initiatives.
- Establishing feedback loops which can support systems change efforts. This could include conducting a survey for families, self-assessment and analysis, or quarterly family organization forums to connect and establish a feedback loop.

Innovation Area Networking

The goal of the Innovation Area Networking Breakout was to provide an opportunity for participants to connect with their peers according to the innovation area they were most interested in discussing. This time allowed individuals to meet others from around the country and network related to a particular interest/innovation area specific to practice, policy, and strategic innovations. This was also a time to take the general observations or “lessons learned” from the last session breakouts and apply them to a specific innovation hub. Key takeaways – or “tips and tricks” - from each Innovation Area are summarized below:

Self-Advocate and Family Engagement:

- Smaller and more regional collaboratives are generally more successful than large groups
- Doing ‘duos’ or partners where more than one self-advocate or family member co-drive and facilitate
- Focusing on success stories of different projects and what is happening
- Working with cultural brokers to better understand how to facilitate those meetings and make them fun

Quality:

- Everyone approaches quality differently; the question is how to connect and collaborate as states to make the system better for individuals and families
- Several states incorporating NCI into quality measures at different levels

Front Door:



- It's about the user experience – coming to the door, being received, heard, and supported
 - o How is the referral being made?
 - o Are individuals being connected with others in the community?
- Understanding how to conduct self-evaluations of work to identify what the initial issues are and where to start, and then identify where to go

Person Centered Planning (PCP):

- Supporting people in rural places with less resources - leveraging integrated supports, considering self-direction
- Embedding CtLC tools and principles in planning processes, assessment tools, and documents – some already existing and some being created
- Creating resources for families and individuals so they can learn more about PCP

Cross Agency Collaboration and Connections:

- Starting with representatives that cross the system, finding the connections
- Connecting over highlighting the successes of other agencies -- showing the WHY and the impact, especially how the CoPs can highlight success and being able to share so that everyone knows that other systems are using the framework

State Huddles

Each state then had the opportunity to “huddle” as a team to continue networking and fostering connections with peers from their state. States were encouraged to take this opportunity to reflect and share ideas for next steps that can be shared with the state's National TA lead, who can support planning for and implementation of identified priorities.

Sharing, Reflections, Wrap Up and National Team Updates

To end the annual meeting, states shared their “takeaways” and “aha moments” as well as ideas for moving forward and continuing to work with one another.

National Team Updates:

1. The National Team announced that the Innovation Roundtables will be starting again in July, with more information and Zoom connection to follow.
2. The National CoP Team shared an exciting announcement, the launch of a new and improved Community of Practice website.



- a. The CoP will be releasing the full website very soon, but a preview of the brand-new state web pages was shared. These pages will provide states with an updated virtual location to share their innovations and successes, and they can check out what other states are working on and connect.
3. Quarterly CoP Mentoring Sessions for CoP leadership series and CtLC Ambassador Series graduates, along with their state lead facilitators, to support state CoP teams to identify how to best leverage CtLC Ambassadors in ongoing state system change priorities and efforts. Mentoring sessions will include:
 - a. Grassroots Leadership Mentoring for “person in the context of the family grassroots implementation” This will entail practice coaching to expand knowledge and practical application of family and self-advocacy engagement, outreach, connections, and leadership at the local and state levels.
 - b. Systems Change Leadership Mentoring -This mentoring will focus on both state-specific and cross-state strategies on how to develop practical actions through design thinking that can be applied to priority state systems change.

The meeting ending with the National Project Team thanking CoP member states for their passion in assisting states in their collective endeavor to support individuals with I/DD and their families to have good lives in the community.