



COMMUNITY OF PRACTICE FOR SUPPORTING FAMILIES NEBRASKA STATE TEAM

Community of Practice for Supporting Families Nebraska Annual Technical Assistance Visit Summary April 7-8, 2025

Background:

The National Community of Practice (CoP) for Supporting Families of Individuals with intellectual or developmental disabilities (I/DD) originally began in 2012 as a project funded by the Administration for Intellectual and Developmental Disabilities. The initiative began as a collaboration between Connecticut, District of Columbia (DC), Oklahoma, Tennessee, Washington, and Missouri (as the mentor state), with the goal to build capacity through a community of practice across and within these states to create policies, practices, and systems to better assist and support families that include a member with I/DD across the lifespan. The overarching goal of the National CoP for Supporting Families is to enhance the capacity of states and communities to create policies, practices, and systems that better assist and support families who have a member with I/DD across their lifespan. This involves building a network for sharing knowledge, fostering innovation, and promoting sustainable systems change to empower families and improve their well-being.

Now twenty-two states strong, the National CoP for Supporting Families continues to support member states to:

- Listen to and learn from families of people who have disabilities about the way that systems can best change to support people across the lifespan
- Creating a feedback loop with the system to cultivate mutual support and accountability between the system and grassroots (families and self-advocates)
- Leveraging partnership that enables systems to have growth and connectivity to effectuate culture change for systems innovation
- Innovating and sharing learning about best and promising practices, innovations, and implementation strategies for person- and family-centered practices and policy enhancement

Nebraska Department of Health and Human Services, Division of Developmental Disabilities (DDD) joined the National CoP in early 2022 with the goal of revising and strengthening the person-centered planning process for people who use services in the I/DD and Aging and Physical Disability systems. Since that time, the Nebraska Council on Developmental Disabilities (NCDD) and DDD have made significant investments in training various partners to be CtLC Ambassadors with the goal of strengthening the person-centered planning process in the state of Nebraska across multiple service populations. In addition, Nebraska developed and implemented a Family Support Waiver with the goal of providing services to people under the age of twenty-one living with their families and has most recently been able to eliminate the Waiting List for developmental disabilities (DD) waiver services.

Purpose of the Technical Assistance Sessions:

The technical assistance (TA) visit from the National CoP Team was used to facilitate a gathering of the NE CoP leadership team including representation from DDD and NCDD personnel, CtLC Ambassadors, family members, other NE Department of Aging and Disability personnel, and people with lived experience to engage in conversation to further



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develop the Vision for Supporting Families Across the Lifespan in Nebraska. The aim of the on-site technical assistance visit was to bring people to:

- Share, reflect and celebrate the work of the Nebraska CoP since its beginning in 2022.
- Understand more about the goals of the National Community of Practice and how these goals impact the work of the Nebraska CoP.
- Develop a shared vision and goals, with consensus around needed actions and specific roles/opportunities to leverage strengths, collaborate and partner.
- Develop a plan to leverage investment from NCDD and DDD on CtLC Ambassadors in Nebraska to advance the vision and goals of the Nebraska CoP.

With the foundational work of redesigning the Person-Centered Planning (PCP) process the Nebraska (NE) CoP desires to engage their Ambassadors to develop and implement the vision for supporting families in the person-centered planning process and supporting the person within the context of the family.

Stakeholder Cohorts Summary:

The first day of the visit consisted of two cohorts of stakeholders meeting separately to learn about the goals of the National CoP, the work of the Nebraska CoP, and to gather input into the Nebraska Vision for Supporting Families across the lifespan. Both cohorts consisted of family members, people with lived experience, community advocacy organizations, DDD personnel, NCDD personnel, provider organizations, and Service Coordinators.

Attendees spent time working in small groups to develop a vision for supporting families in Nebraska using the Life Trajectory tool which included what was not wanted in the system in respect to supporting families, past experiences that either advanced the vision or proved problematic in achieving the vision, and discussion of future action steps that would be helpful in advancing the vision.

Vision for Supporting Families in Nebraska:

- **Families need accessible** - user-friendly information to navigate services which includes flowcharts, accessible language, and cross-agency sharing.
- **We must strengthen transitions** - addressing this from 'child to adult' services with better education for families, schools, and providers.
- **Families and individuals deserve a voice in shaping their support** - this means person-centered planning and inclusive decision-making.
- **Collaboration is key** - we must collaborate with schools, medical providers, community businesses, and chambers of commerce.
- **We need innovation and flexibility** - in waivers, housing, transportation, employment, and use of technology.

What We Do Not Want:

- **Overwhelmed families** - red tape, confusing processes, and limited access to vital information.
- **Isolation and segregation** - families feeling unheard or unsupported.
- **Institutionalization as a default** - fight for inclusive, community-based supports.



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- **Funding** to drive decisions over people's needs.
- **Inconsistency and lack of training** - for Providers and Service Coordinators (SC), this can negatively impact families, better education is essential across all roles.

💡 Strengths to Build On:

- **Strong advocacy and leadership** - we can expand on CtLC, PCP, and urban service models.
- **Families, providers, and leaders** - we must all be open to feedback and current ideas.
- **Technology, shared learning, and ambassador roles** - these are foundations to grow from and increase momentum.
- **Transparency and collaboration** - we should increase and reinforce these trends with system-wide support.

📦 Barriers We Must Address:

- **Direct Support Professional (DSP) shortages and inconsistent training for providers and SCs** - this limits access and quality.
- **Rural families face major service gaps** - expansion and creative solutions are needed.
- **Cultural and language barriers** - this prevents equitable access.
- **The system is complex and discouraging** - simplification and navigation help are critical.
- **Lack of preparation for aging caregivers and transitions** - this creates fear and instability for families.

✅ Next Steps

As Individuals:

- Keep the conversation going - share, train, and advocate.
- Use and promote CtLC tools and person-centered practices.
- Check in with families, break down barriers, and encourage dignity of risk.

In Organizations:

- Prioritize listening and acting on self-advocates and family input.
- Improve training, collaboration, and communication across teams.
- Build connections to community resources and employment opportunities.

At the Policy Level:

- Waivers and EVV - reform the rules to be more person-centered.
- Educate legislators about real family experiences and system needs.
- Push for more flexible funding, support for aging caregivers, and cross-agency planning.

Nebraska CtLC Ambassadors:

Since 2020, NCDD has made a significant investment in PCP, NE Ambassadors, and the CtLC Framework. NCDD and DDD recognized the opportunity to leverage the skills, passion, resources, and community connections from this group of Ambassadors to further develop action steps toward the Vision for Supporting Families.

Nebraska Ambassador Cohort Summary:

The second day of the TA visit began with a cohort of Nebraska's CtLC Ambassadors. The Ambassadors have expressed interest on improving the vision of supporting families and some were already hosting small groups across the state to support Nebraska's person-centered planning



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initiatives. Information collected from the two cohorts on the first day was reviewed with the Ambassadors in addition to conversations about how families are currently involved in person-centered planning in Nebraska and how families engage on all levels including policy and systems change.

1. Family Engagement:

- **Building Relationships**
 - Informal, person-centered interactions
 - Relatability and modeling
 - Long-term staff as family
- **Planning & Involvement**
 - Accumulate info year-round
 - Include families and DSPs at planning meetings
 - Focus on life stages and family system experience
 - Transportation and time barriers
- **Supportive Practices**
 - Options to avoid burnout
 - Share experiences, community involvement
 - Use relatable language and approaches

2. Cross-System Collaboration:

- **Key Collaborators**
 - HIC/Parent Training Information, Nebraska's University Center for Excellence in Developmental Disabilities, Munroe-Meyer Institute, The Arc of Nebraska, Educational Services Units, Vocational Rehabilitation, and waiver providers
- **Approaches**
 - Regional support for schools
 - Use of natural supports
 - Emphasize day-to-day involvement
 - Habilitative options for learning

3. Reaching Families Outside the System:

- **Barriers**
 - Language
 - Culture
 - Poverty
 - Families often do not have extra time
 - Misunderstanding services/supports
- **Strategies**
 - Hospitals and medical professionals
 - Teachers, educators, Multidisciplinary Team tools, events at schools
 - Informal outreach (coffee shops, churches)
 - Social media as a tool for tips and info
 - Peer support, informal and formal support groups



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4. Planning Meetings & Service Coordination:

- **Improvements Needed**
 - SC mindset shift; better integration with partners
 - Early and structured consent
 - Connect SCs to agendas and transitions
- **Challenges**
 - Disconnect with schools
 - Early graduations with no plan
 - Summer services gap

5. Action Steps:

- **Engagement & Outreach**
 - Town halls, videos, ambassador follow-ups
 - Use of challenges, networking, saturation strategies
- **Framework & Tools**
 - Focus on framework, not just the tools
 - Align provider goals with individual goals
 - Embed tools in Case Management systems (e.g., Therap)
- **System Improvements**
 - Update policy manual
 - Budget for ambassador work
 - Clarify expectations and implementation

Wrap-up and Debrief:

Finally, the end of the second day of the TA Visit was concluded by meeting with the Nebraska CoP and the National Leadership Team, including additional senior personnel from DDD. Tony Green, Director of DDD was also in attendance. The CoP Leadership Team met to review all input from the three cohort meetings regarding the Vision for Supporting Nebraska Families, how Ambassadors can support the vision, and prioritizing next steps for the Nebraska CoP moving forward.

Nebraska Priorities

DDD and NCDD Key Areas for Next Steps

Support for Families

- Provider report cards - include ambassador numbers, use of CtLC/PCP, innovations
- Think through roadblocks to peer support in Family Support Waiver
- Education for SC's regarding school age specifically (unless there is already training available and just need to reach different age group)

HCBS System to Focus on Families

- Start tracking data of the students entering DHHS
- Leverage special health care programs and Family Support Waiver to improve transition



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Activities Focused on Family within Schools

- Fund ambassador training for transition staff
- Work with the State Department of Education staff to attend transition trainings regarding CtLC
- Explore consent form opportunities to include SCs in planning meetings
 - The SC, family, teacher, program writers (and other key members of the student's team) should all be at the IEP meetings to better strengthen the students learning and growth within their own transition solutions
- How to engage with schools to push for full days, employment exploration, and no early graduation

Other Area

- Create an Ambassador Directory
- Create the outline for an Ambassador Structure
 - Build up the collective strategy from the CoP
 - Be empowered within this group
 - Examples of what can be done for each field
 - Attend the monthly NE CtLC Ambassador Workgroup
 - Leave some room for innovative solutions
 - How to communicate the structure and keep the momentum
- Update HCBS Publications for stakeholders that embrace CtLC and PCP
- Define key areas for responsible parties of action steps across the state
- Take “inventory” of where money is going for ADRCs to educate families
- The Early Development Network presentation to embed the mindset
- Defining levels for ambassadors such as potential badges for some
- Identify who will oversee initiatives such as PCP, tech 1st, employment 1st

Ambassadors' Key Areas for Next Steps

Support for Families

- Empower families to ask the right questions so their needs are met
- Update Along the Way guides
- Educate families on the resources and options that they have

HCBS System to Focus on Family

- Educate SC's and Providers on the positive mindset shift
- Be more creative with CtLC when working on personal goals
- Implementation of CtLC year round

Activities Focused on Family

- Educating families on the mindset of CtLC and what it can offer
- implementation of CtLC further than just ISP meetings



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Other Areas

- Discuss what occurs during the Nebraska CtLC Ambassador Workgroup
- Have different specializations based on strengths and their role

Recommendations from the National CoP Team:

Considering the volume of next steps discussed with the Nebraska CoP Leadership team while onsite in Nebraska, it may benefit the team to choose a couple of next steps to prioritize and focus on over the next year. Consider next steps that are attainable and will make a broader impact on advancing the Nebraska Vision for Supporting Families. It would be beneficial for the Nebraska CoP to continue meeting with families and people with lived experience to further define the next steps identified during the onsite TA visit. For example, one of the recommended next steps is to develop provider report cards. Before embarking on work there it would be helpful to know from families - What information in a provider report card would most benefit families and people who are aging and/or have disabilities? How could a family best access a provider report card? Another action step is to think through roadblocks with peer support in the Family Support Waiver. Again, it would be most helpful to hear from families about the roadblocks, what issues they are facing, and what they think might be practical solutions.

Given the need for additional input from families regarding the action steps, it would be helpful for the Nebraska CoP to take an inventory of current opportunities for family input and develop a plan to capitalize on the opportunities in an organized manner. The CtLC Ambassadors would be an excellent partner in helping to structure opportunities to receive formal feedback from families in Nebraska.

Finally, since the Nebraska CoP team is focusing on system and culture change, it is important to ensure that all areas of Nebraska DDD are familiar with the work of the CoP, understand their role in the desired vision, and are equipped to take action in their respective bodies of work to better support families of Nebraskan's of people who are aging or have disabilities across the lifespan.

Conclusion:

The Nebraska Community of Practice for Supporting Families team has accomplished many incredible things during their time with the national team. Their focus on person-centered planning, embracing, and implementing the CtLC Framework, building up a cohort of 53 CtLC Ambassadors (and growing), and working to create a state-wide Ambassador Directory has resulted in many positive changes to the planning process for people with disabilities or who are aging. The input gathered at the TA visit and a plan for continued feedback from families will help to continue to define priorities and next steps in the vision for better supporting families.