

# Supporting Families Community of Practice Evaluation

## Missouri State Data Brief

### Evaluation Overview

In 2012, the Administration for Community Living (ACL), through the Administration on Disabilities (AoD)<sup>1</sup>, awarded the five-year National Supporting Families Community of Practice (CoP) grant to the National Association of State Directors of Developmental Disabilities Services (NASDDDS), which partnered with the University of Missouri-Kansas City Institute on Human Development (UMKC-IHD). In the first year of the grant, 15 states applied and five were selected to participate, including Connecticut, the District of Columbia, Oklahoma, Tennessee, and Washington, with Missouri serving as the mentor state. Given growing interest in the work of the CoP, NASDDDS and UMKC-IHD decided to expand and sustain the CoP outside of the initial grant. A second cohort, known as the expansion states, joined in 2016, including Alabama, Delaware, Hawaii, Indiana, Kansas, Maryland, Ohio, Oregon, Pennsylvania, and South Dakota. With interest continuing to grow around the nation, the CoP welcomed five new states—Massachusetts, Michigan, Minnesota, Virginia, and New Jersey—in 2019 and created opportunities for participating states to adjust their level of participation.

Three project outcomes guide the work of the National Supporting Families CoP:

- State and national consensus on a national framework and agenda for improving supports for families with children with I/DD
- Enhanced 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

To examine progress toward federal project outcomes and identify which activities are leading to success, ACL funded the National Supporting Families CoP evaluation. The evaluation team gathered data that align with the three project outcomes to determine how the CoP is producing outcomes of interest to ACL, which reflect the five AoD priority areas (Exhibit 1). Findings will provide ACL with outcomes data and recommendations to improve supports to families of individuals with I/DD. They will also provide information on how the CoP and CtLC framework improve support and systems delivery of services to families and individuals with I/DD.

### Exhibit 1. AoD Priority Areas

The Five AoD Priority Areas
▪ Ensure the continued protection of rights of individuals with I/DD and prevent their abuse, neglect, and exploitation
▪ Improve and maintain effective and responsive management of responsibilities under Developmental Disabilities Assistance and Bill of Rights Act of 2000 (the DD Act)
▪ Promote Employment First as a key strategy for individuals with I/DD to be contributing and productive members of society participating in the competitive integrated workforce
▪ Empower individuals with I/DD and their families to access home and community based (HCBS) and supports that are self-directed and ensure opportunity for community participation
▪ Support advocacy efforts of individuals with I/DD in order to ensure their participation in system and service delivery design

<sup>1</sup> The Administration on Intellectual and Developmental Disabilities (AIDD) initiated the evaluation in 2017. The Administration on Disabilities (AoD) now oversees the evaluation.

The evaluation includes all 16 states that participated in the National Supporting Families CoP for at least two years between 2012 and 2018. For evaluation purposes, evaluators stratified states into three groups based on their stage of development, as described in Exhibit 2.

### Exhibit 2. Evaluation Participants

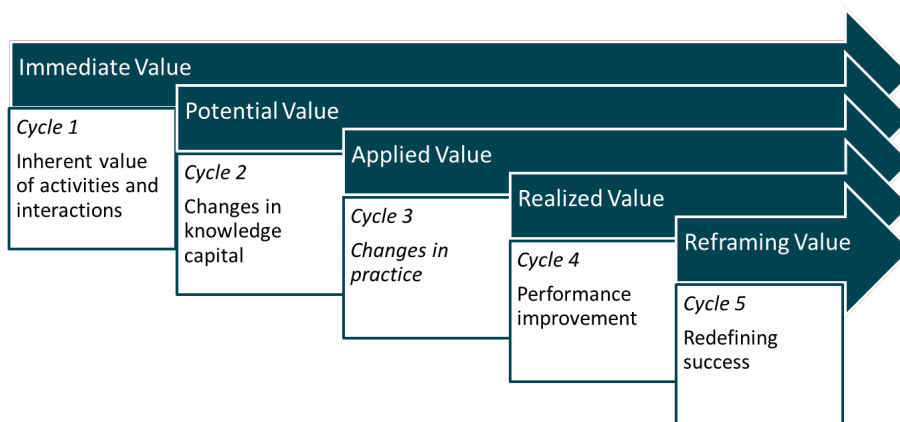
Group One	Group Two	Group Three
<p><b>The six original CoP states:</b></p> <ul style="list-style-type: none"> <li>▪ Connecticut</li> <li>▪ District of Columbia</li> <li>▪ Missouri (mentor state)               <ul style="list-style-type: none"> <li>▪ Oklahoma</li> <li>▪ Tennessee</li> <li>▪ Washington</li> </ul> </li> </ul>	<p><b>States with previous exposure to the CoP and CtLC framework before joining the expansion state cohort:</b></p> <ul style="list-style-type: none"> <li>▪ Maryland</li> <li>▪ Ohio</li> <li>▪ Pennsylvania</li> <li>▪ South Dakota</li> </ul>	<p><b>States with little or no exposure to the CoP and CtLC framework before joining the expansion state cohort:</b></p> <ul style="list-style-type: none"> <li>▪ Alabama</li> <li>▪ Delaware</li> <li>▪ Hawaii</li> <li>▪ Indiana</li> <li>▪ Kansas</li> <li>▪ Oregon</li> </ul>

Evaluators collected data from states using four tools:

- *Reporting tools* (one for each state grouping) gathered descriptive data about CoP structure, activities, and impact.
- *Telephone interviews* (informed by the reporting tools) collected contextual data about CoP activities and accomplishments specific to each state.
- *Site visits* (to select states) with CoP leadership and other stakeholders provided data on the relationship between CoP activities, outputs, and outcomes.
- *Materials review* (on an ad-hoc basis) collected needed data on areas of interest.

Evaluators analyzed the collected data using a conceptual framework developed by Wenger, Trayner, and de Laat<sup>2</sup> (Exhibit 3), which assesses value creation in communities. Adapted for evaluation purposes, the framework considers five different cycles of value creation to capture the richness of value created by communities of practice. The following page describes the value generated from CoP activities and the CtLC framework within the Missouri CoP.

### Exhibit 3. Value Cycle Framework

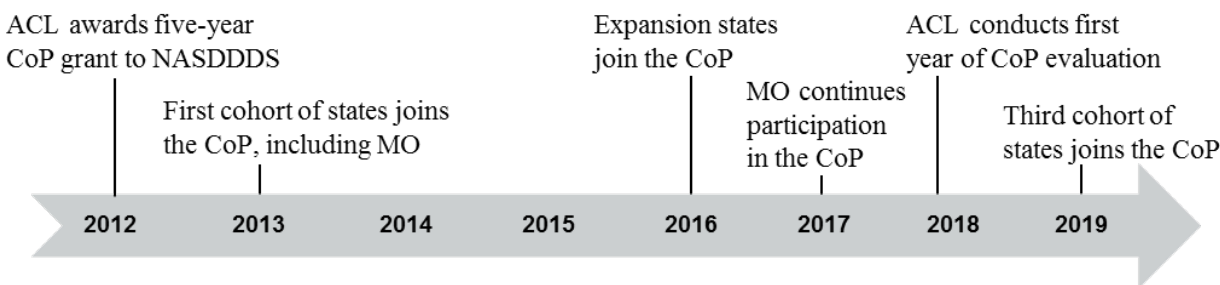


<sup>2</sup> Wenger, E., Trayner, B., and de Laat, M. (2011). Promoting and Assessing Value Creation in Communities and Networks: A Conceptual Framework. Rapport 18, Ruud de Moor Centrum, Open University of the Netherlands.

## A Look into Missouri's Community of Practice

Missouri (MO) is one of the six original states to join the National Supporting Families CoP in 2013. The MO CoP is a collaboration between the Missouri Developmental Disabilities Council (MODDC) and the Missouri Division of Developmental Disabilities (DD). The timeline below (Exhibit 4) provides detailed information about MO's participation in the CoP over time.

**Exhibit 4. Timeline of Missouri's CoP Participation**



Using data from the most recent Residential Information Systems Project Report developed by the University of Minnesota, the number of people with I/DD known to or served by the MO Division of DD in 2016 was 34,802. Long-Term Services and Supports (LTSS) recipients include people with I/DD who receive Medicaid or State-funded supports and services. In 2016, 58% of 18,704 LTSS recipients in MO lived at home with a family member. The report also shows annual Medicaid Waiver expenditures for recipients with I/DD, which amounted to \$56,064 per recipient in 2016.<sup>3</sup>

Understanding the current state of I/DD services and supports in MO is important in better understanding how CoP activities and the CtLC framework impact families and individuals with I/DD. The evaluation team gathered valuable data from MO through administration of the reporting tool, telephone interview, and materials review. After careful analysis of the data using the value cycle framework, the evaluation team noted the following key achievements by Connecticut's CoP during evaluation year one:

- Various state agencies and stateside organizations have incorporated the CtLC framework, including Vocational Rehabilitation (VR), Early Childhood, Special Health Care Needs, Protection & Advocacy, First Steps, Project STIR, and the Missouri Association of County Developmental Disabilities Services. Among them, they work to develop, fund, and disseminate CtLC resources.
- The MO Division of DD uses the CtLC framework and tools to create strategic plans for various projects and initiatives, and to help plan DD Council members' orientations and retreats.
- UMKC has uploaded CtLC trainings online for families to access at no cost.

<sup>3</sup> Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Bourne, M.L. (in press, 2018). In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2016. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

MO's continued participation in the National Supporting Families CoP shows their commitment to the CtLC framework and advancing supports for families of individuals with I/DD. The following tables includes a more comprehensive list of MO's achievements from evaluation year one.

**Exhibit 5. Missouri's Achievements in Evaluation Year One, 2018-2019**

Value Cycle	CoP Activities and Achievements
<b>Cycle 1: Immediate Value</b> <i>Value of Activities and Interactions Themselves</i>	<ul style="list-style-type: none"> <li>▪ The MO CoP provides peer-to-peer support for families and self-advocates.</li> <li>▪ The Developmental Disabilities (DD) Council works closely with county boards and invites them to all CoP meetings and events. Self-advocates also work in each regional office.</li> <li>▪ Stakeholder meetings occur four times a year. Attendees include representatives from the DDD, Aging, Health &amp; Senior Services, DD Council, families, and self-advocates.</li> </ul>
<b>Cycle 2: Potential Value</b> <i>Changes in Knowledge Capital</i>	<ul style="list-style-type: none"> <li>▪ In a joint project around Supported-Decision Making, MO uses the CtLC tools in stakeholder trainings to articulate alternatives to guardianship.</li> <li>▪ This past year, three cohorts of individuals went through the Ambassador Series training.</li> <li>▪ The MO Family to Family (F2F) Stakeholder group comes together to work on networking, sharing resources, and referrals to further streamline access to services for individuals with I/DD and their families. F2F is also actively enhancing front door supports through the Division of DD.</li> <li>▪ Progressive Community Services (PCS) hired family navigators who work with self-advocates and family members who are not yet eligible for services to create a trajectory, think about possibilities, develop a vision for a good life, plan, etc.</li> </ul>
<b>Cycle 3: Applied Value</b> <i>Changes in Practice</i>	<ul style="list-style-type: none"> <li>▪ The Division revised its individualized support plan (ISP) process and Support Coordinator Guidelines to align with CtLC. Several county boards adjusted their ISP as well.</li> <li>▪ MO created several new staffing positions within its Division, including information specialists hired to assist in Medicaid access and eligibility determination in regional offices.</li> <li>▪ Important policy changes, such as adjustments to the Guardianship Law, took place this past year.</li> <li>▪ Project STIR created a "LifeCourse University" in order to serve as a community focal point for working through goals.</li> </ul>
<b>Cycle 4: Realized Value</b> <i>Performance Improvement</i>	<ul style="list-style-type: none"> <li>▪ No activities reported during this evaluation period.</li> </ul>
<b>Cycle 5: Reframed Value</b> <i>Redefining Success</i>	<ul style="list-style-type: none"> <li>▪ The State DD agency is changing the way it measures outcomes by aligning them with the CtLC framework and life domains.</li> <li>▪ The DD Council reframed its goals and strategies by aligning their five-year plan with the CoP and CtLC framework.</li> </ul>