

Evaluation Findings Brief—Year 1 (2018-2019)

National Community of Practice (CoP) for Supporting Families

Introduction

In 2012, the Administration for Community Living (ACL) awarded the five-year National CoP for Supporting Families grant to the National Association of State Directors of Developmental Disabilities Services (NASDDDS), who partnered with the University of Missouri-Kansas City Institute on Human Development (UMKC-IHD). The National CoP builds capacity across and within state participants to improve and create policies, practices, and systems that better support families of individuals with intellectual and developmental disabilities (I/DD).

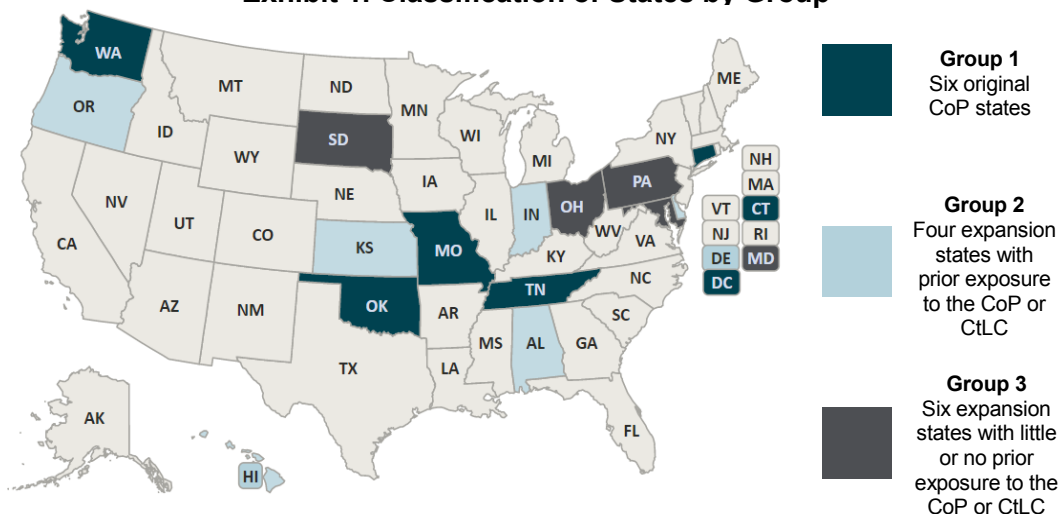
Charting the LifeCourse (CtLC)

Designed by UMKC, the CtLC framework is a set of principles to help individuals and their families identify and find supports, assess their options, and envision their best life. The framework is based on the following core belief: “All people have the right to live, love, work, and play and pursue their dreams in their community.”

Evaluation Approach

To assess progress towards national project outcomes and identify successful emerging practices that improve supports for families of individuals with I/DD, ACL awarded an evaluation contract to New Editions Consulting and its partner, The Lewin Group (the evaluation team). The evaluation includes 16 states that participated in the National CoP for at least two years between 2012 and 2018. The evaluation team classified states into three groups based on when they joined the national CoP and their prior experience to the CtLC framework (Exhibit 1).

Exhibit 1. Classification of States by Group

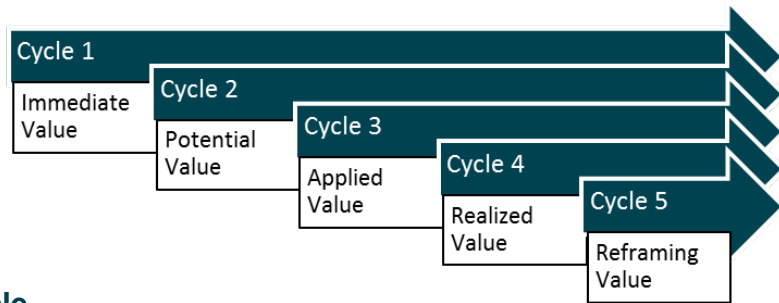


The evaluation team used four different tools to collect data from states: reporting tools, telephone interviews, site visits (to select states), and materials review (on an ad-hoc basis). Using the value cycle framework¹, the evaluation team analyzed data and linked specific activities with outcomes of interest (Exhibit 2).

¹ Adapted from 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

Exhibit 2. Value Cycle Framework

National CoP Project Outcomes
State and national consensus on a national framework and agenda
Enhanced state policies, practices, and sustainable systems
Enhanced capacity of states to replicate and sustain exemplary practices

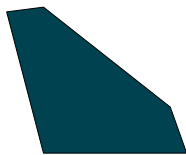


Evaluation Findings by Value Cycle

Cycle 1: Immediate Value

Immediate value refers to activities that may facilitate policy and practice changes in later cycles and contribute to improved supports and individual outcomes.

- **Stakeholders share information and provide support.** State CoP members share progress towards goals, initiatives, events, and CtLC tools and resources. CoP members use social networking and peer-to-peer support to build community. On a national level, state CoPs share initiatives and information among each other.
- **Family members and self-advocates guide the agenda.** They are part of CoP leadership and inform service and supports, processes, and policies.
- **States structure their organization based on needs and context.** Some states have a formal, hierarchal structure while others use informal, grassroots-led strategies. Some states employ the use of regional or local CoPs. On a national level, select states reported benefiting from meetings and technical assistance (TA) from the national project team.
- **Diverse partnerships engage and collaborate around a shared purpose.** Partners include, but are not limited to, family advocacy organizations, provider agencies, education systems, employment initiatives, aging departments, Vocational Rehabilitation, University Centers for Excellence in Developmental Disabilities (UCEDDs), and Protection and Advocacy Systems (P&As).



In Delaware, the Division of Developmental Disabilities Services (DDDS) collaborates with the Division of Medicaid & Medical Assistance (DMMA) and Division of Services for Aging and Adults with Physical Disabilities (DSAAPD) to develop supports for family caregivers of individuals with Dementia and Alzheimer's.

Netherlands. Retrieved from http://wenger-trayner.com/wp-content/uploads/2011/12/11-04-Wenger_Trayner_DeLaat_Value_creation.pdf.

Cycle 2: Potential Value

Potential Value includes use of the CtLC framework, family outreach, product development, advancement of current initiatives, and changes in thinking or knowledge that are expected to produce value in later cycles.

- **State CoP use of the CtLC framework creates a common language.** The CtLC framework helps individuals and families develop their vision for a good life, think about options, and identify supports. Organizations adopt CtLC and use the framework to prioritize strategies and evaluate activities.
- **States use diverse strategies to build knowledge.** State CoPs offer formal and informal CtLC trainings. Stakeholders integrate the framework into initiatives on assistive technology, employment, self-determination, and planning services.
- **States advance new and current initiatives for growth.** Focus areas include enhancing front door supports, including more voices in services and support planning and implementation, and improving employment, education, supports, and capacity building.

The Connecticut Department of Developmental Services (DDS) and Council on Developmental Disabilities (CDD) provide the Ambassador Series and other training opportunities to families, self-advocates, and professionals (e.g., case managers, Department of Education, and Department of Rehabilitation Services).



Cycle 3: Applied Value

Applied value refers to the ways that knowledge leads to changes in practices, such as innovation, new approaches, or changes in policies, programs, or services.

- **States change policies and services to advance supports to families.** Examples include new waivers embedded with the CtLC framework. States also implemented new waiver services, passed legislation, such as the Technology and Employment First Act, and revised service eligibility guidelines.
- **States revise forms and processes to align with the CtLC framework.** States used the CtLC framework to revise ISPs, administrative policies and procedures, hiring and recruitment processes, and intake and referral processes. Several states created new staff positions to support collaboration and reported increased capabilities.



Indiana created a Person Centered Individualized Support Plan (PCISP) that reflects the CtLC life stages, life domains, and strength-based supports. The state is now measuring the completion of PCISPs for all individuals.

Cycle 4: Realized Value

Realized value refers to the effect of new practices from Cycle 3. Impacts include decreased reliance on formal services, reduced waiting lists and processing times, and better lives.

- **People behave in new and different ways.** Family members increased their involvement in planning and focused on what they want through the lifespan, not just what they want from services. Staff engaged in person-centered planning now approach the process with a greater focus on the individual in the context of the family unit, rather than focusing on the individual. Agency staff are more likely to consider the individual and family's needs first, then offer appropriate service options, as opposed to only providing service options.
- **State services operate more efficiently.** More people are receiving community-based services with greater efficiency and access. States have reported reductions in waiting list and processing time due to policy changes.

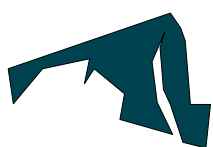
Pennsylvania's Employment First Act of 2018 expanded employment opportunities for individuals with disabilities. Over the last two years, there was an increase from 12% to 16% of the proportion of the population of individuals with I/DD with competitive employment.



Cycle 5: Redefining Success

Redefining success refers to new strategies for measuring outcomes and program sustainability. Additionally, this category refers to changing goals, strategies, or system operations as a result of changes in knowledge capital and practice in earlier cycles.

- **State CoPs advance new goals, strategies, and operations.** States see the CtLC embedded into DD quality outcomes, strategic plans, and evaluation methods with an emphasis on community resources.
- **States measure outcomes in new ways.** This often involves embedding the CtLC framework into projected work plans and evaluation methods.



In Maryland, local CoP leaders voiced that national or state teams made organizational decisions without outside consultation. In response, state CoP leadership brainstormed ways to better include local CoP input, such as new circular pipelines of information between the state and local groups.

Learn More

The Office of Performance and Evaluation (OPE) has a webpage with more information on the National CoP for Supporting Families evaluation, among other projects, and is where more comprehensive findings of this year's evaluation cycle will be available.

<https://acl.gov/programs/program-evaluations-and-reports>

Next Steps

The evaluation team will continue to collect and analyze additional data during the 2019-2020 evaluation cycle of the National CoP for Supporting Families evaluation.