

Supporting Families Community of Practice Evaluation

Delaware State Data Brief

Evaluation Overview

In 2012, the Administration for Community Living (ACL), through the Administration on Disabilities (AoD)¹, 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

¹ 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

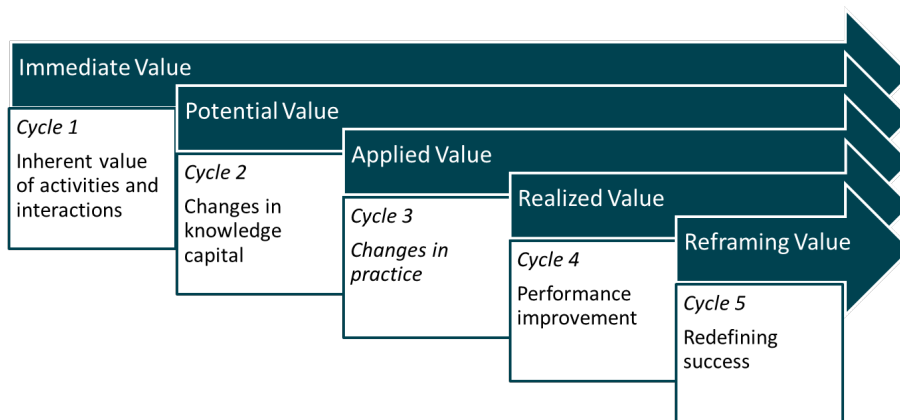
Group One	Group Two	Group Three
<p>The six original CoP states:</p> <ul style="list-style-type: none"> ▪ Connecticut ▪ District of Columbia ▪ Missouri (mentor state) <ul style="list-style-type: none"> ▪ Oklahoma ▪ Tennessee ▪ Washington 	<p>States with previous exposure to the CoP and CtLC framework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

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 Laat² (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 Delaware CoP.

Exhibit 3. Value Cycle Framework

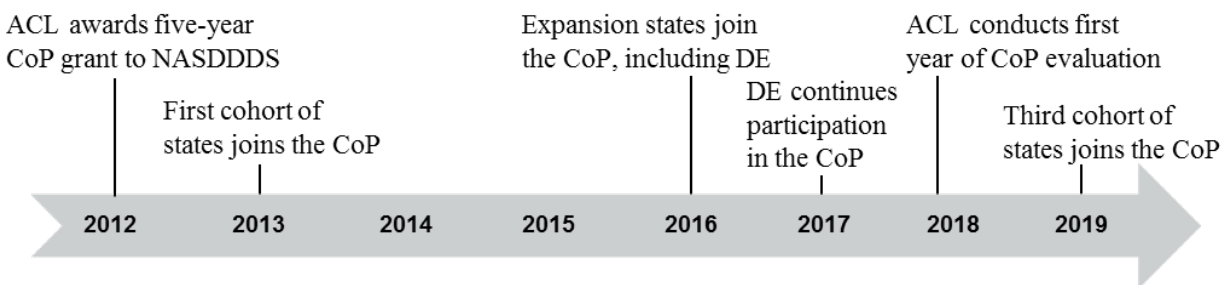


² Wenger, E., Trayner, B., and de Laat, M. (2011). Promoting and Assessing Value Creation in Communities and Networks: A Conceptual Framework. Rapport 18, Ruud de Moor Centrum, Open University of the Netherlands.

A Look into Delaware's Community of Practice

Delaware (DE) is one of the expansion states to join the National Supporting Families CoP in 2016. The DE CoP leadership includes the Division of Developmental Disabilities (DDDS). The timeline below (Exhibit 4) provides detailed information about DE's participation in the CoP over time.

Exhibit 4. Timeline of Delaware'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 DDDS in 2016 was 4,657. Long-Term Services and Supports (LTSS) recipients include people with I/DD who receive Medicaid or State-funded supports and services. In 2016, 71% of 4,579 LTSS recipients in DE lived at home with a family member. The report also shows annual Medicaid Waiver expenditures for recipients with I/DD, which amounted to \$111,093 per recipient in 2016.³

Understanding the current state of I/DD services and supports in DE 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 DE 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 determined the following to be DE's key achievements during evaluation year one:

- Due to DDDS's recent changes to the Human Rights Committee policy, individuals who need behavior supports involving a restriction of rights will be assured that:
 - Any approved restriction is critically evaluated for desired impact;
 - All other options have been exhausted; and
 - The restriction is not a "death sentence" for that particular right, but rather a person-centered approach to enhance the person's well-being and life choices.
- DDDS added the following service categories and expanded eligibility for the Life Span Waiver:

³ 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.

- Development of the Medical Residential Habilitation service to help individuals with high needs to remain in their community who would otherwise generally be placed in a skilled nursing facility or a developmental center;
- Development of the Community Participation service to increase individual involvement in making everyday choices; and
- Expansion of the Supported Living services so that non-residential service providers are able to deliver this service without a brick and mortar home.

DE’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 DE’s achievements from evaluation year one.

Exhibit 5. Delaware’s Achievements in Evaluation Year One, 2018-2019

Value Cycle	CoP Activities and Achievements
Cycle 1: Immediate Value <i>Value of Activities and Interactions Themselves</i>	<ul style="list-style-type: none"> ▪ CoP leadership and members are engaged in CoP activities. They participate in outreach events, meet with stakeholders to understand their needs, and disseminate information and resources. ▪ 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.
Cycle 2: Potential Value <i>Changes in Knowledge Capital</i>	<ul style="list-style-type: none"> ▪ DDDS redesigned their public website to include disability and non-disability resources. In addition, DDDS plans to launch a Facebook page for stakeholders to communicate with one another. ▪ DDDS formed a Learning Community specifically for Medicaid-authorized Providers to address service delivery changes. ▪ DDDS and one of the local community advocacy groups, We Stand 4 Something, Inc., conducted information sessions about CtLC for families and individuals with I/DD in August and October 2018. ▪ DDDS brought on a Targeted Case Management (TCM) organization to assist families in connecting with their Community Navigator. The TCM provider uses the CtLC tools to plan with families, which makes planning more self-directed.
Cycle 3: Applied Value <i>Changes in Practice</i>	<ul style="list-style-type: none"> ▪ DDDS created three new staffing positions—Manager of Family Engagement and two Assistant Directors of Community Services—to help CoP leadership focus more time and energy on CoP activities. ▪ DDDS implemented the Life Span Plan for individuals living with residential service providers to encourage involvement in the planning process.
Cycle 4: Realized Value <i>Performance Improvement</i>	<ul style="list-style-type: none"> ▪ DE is seeing a higher rate of employment than several years ago as individuals have greater opportunity to choose employment that best fits their needs. ▪ By bringing on a TCM organization, DDDS improved access for families to their Community Navigator. Families told DDDS how pleased they are with their Community Navigator and that they have never enjoyed such access before.
Cycle 5: Reframed Value <i>Redefining Success</i>	<ul style="list-style-type: none"> ▪ In the past, DE focused its efforts on the adult population. However, as the CtLC framework has increasingly influenced the state to take an early intervention approach through strategies such as working in schools. ▪ DE CoP members now use the CtLC framework to (1) steer families and individuals towards considering community resources first, and (2) look at a person and their family versus only services.