

Supporting Families Community of Practice Evaluation

Pennsylvania 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

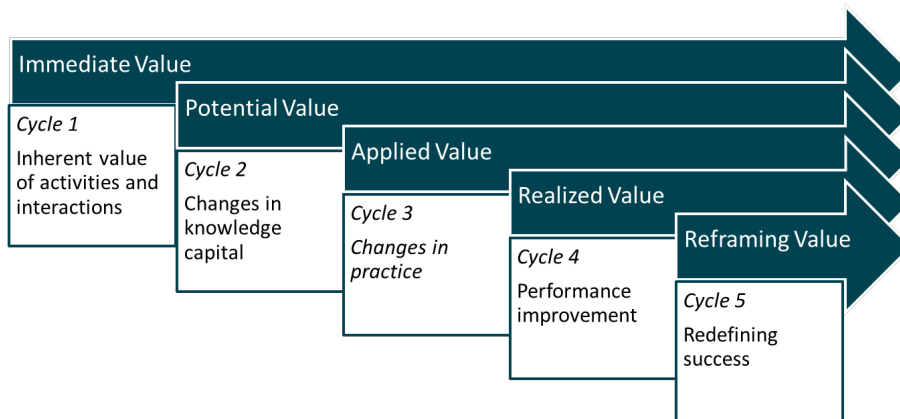
Group One	Group Two	Group Three
<p>The six original CoP states:</p> <ul style="list-style-type: none"> ▪ Connecticut ▪ District of Columbia ▪ Missouri (mentor state) <ul style="list-style-type: none"> ▪ Oklahoma ▪ Tennessee ▪ Washington 	<p>States with previous exposure to the CoP and CtLC framework 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 Pennsylvania CoP.

Exhibit 3. Value Cycle Framework

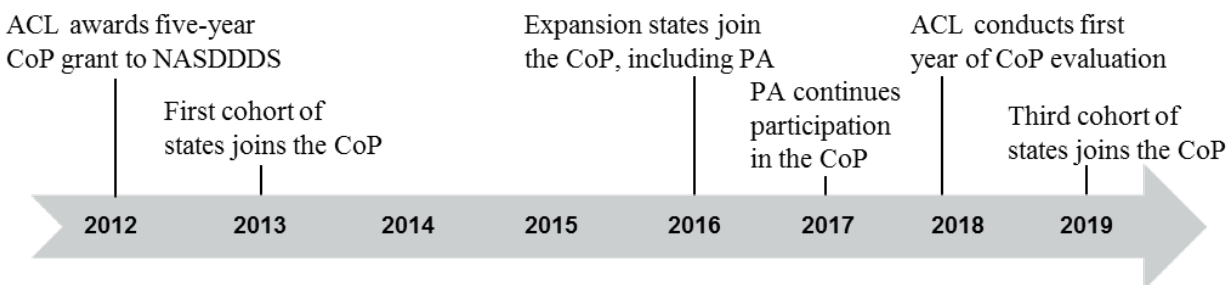


² Wenger, E., Trayner, B., and de Laat, M. (2011). Promoting and Assessing Value Creation in Communities and Networks: A Conceptual Framework. Rapport 18, Ruud de Moor Centrum, Open University of the Netherlands.

A Look into Pennsylvania's Community of Practice

Pennsylvania (PA) is one of the expansion states that joined the National Supporting Families CoP in 2016. The PA CoP is a collaboration among the Office of Developmental Programs (ODP), the PA Family Network, and Self-Advocates United as One (SAU1). The timeline below (Exhibit 4) provides detailed information about PA's participation in the CoP over time.

Exhibit 4. Timeline of Pennsylvania'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 PA Department of Human Services (DHS) in 2016 was 57,517. Long-Term Services and Supports (LTSS) recipients include people with I/DD who receive Medicaid or State-funded supports and services. In 2016, 57% of 57,505 LTSS recipients in PA lived at home with a family member. The report also shows annual Medicaid Waiver expenditures for recipients with I/DD, which amounted to \$74,022 per recipient in 2016.³

Understanding the current state of I/DD services and supports in PA 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 PA 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 PA's CoP during evaluation year one:

- The PA Employment First Act of 2018 expanded opportunities for individuals with Disabilities to gain access to employment.
- As a result of the CoP, PA realized an increase in both the access to and efficiency of services provided by ODP. Examples of this improvement include (1) an increase in the population with competitive integrated employment from 12% to 16%, and (2) an increase in services for individuals with autism.
- PA developed training programs to provide support to a variety of audiences including Administrative Entities (AEs), Supports Coordination Organizations (SCOs), providers, families, and self-advocates. In response to the training, the Office of Vocational Rehabilitation (OVR) has identified an interest in incorporating CtLC principles into its work.

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.

PA’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 PA’s achievements from evaluation year one.

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

Value Cycle	CoP Activities and Achievements
<p>Cycle 1: Immediate Value <i>Value of Activities and Interactions Themselves</i></p>	<ul style="list-style-type: none"> ▪ The CoP structure in PA encourages stakeholders to engage at the local level on an ongoing basis through over 20 local collaboratives. ▪ The PA CoP collaborates with several organizations to address pressing issues within the state, such as sexual abuse and employment. These groups include the PA Family Network, SAU1, and Vision for Equality. ▪ In addition to collaboration between organizations, state agency leadership is becoming involved in the CoP. There is consensus across ODP, OVR, and the Office of Childhood Development and Early Learning.
<p>Cycle 2: Potential Value <i>Changes in Knowledge Capital</i></p>	<ul style="list-style-type: none"> ▪ The PA CoP helps stakeholders identify new ways to simplify business practices to align with CtLC principles. ▪ ODP works collaboratively with DHS to advance employment practices. ▪ CtLC principles will be incorporated into the state’s case management system and new individual support plan (ISPs).
<p>Cycle 3: Applied Value <i>Changes in Practice</i></p>	<ul style="list-style-type: none"> ▪ ODP modified eligibility criteria for the three ID/A Waivers to include self-directed care for individuals with autism. ▪ Other waiver changes are the allowing of relatives to provide transportation, addition of nursing for children’s respite services, and a new Targeted Services Management (TSM) service that offers extended support to families on the waiting list. ▪ PA developed a new training strategy to allow family members to offer Technical Assistance (TA) to and co-facilitate trainings for ODP staff.
<p>Cycle 4: Realized Value <i>Performance Improvement</i></p>	<ul style="list-style-type: none"> ▪ As a result of implementing community participation services, the PA CoP reported a shift in behavior towards increased levels of community participation and family leadership.
<p>Cycle 5: Reframed Value <i>Redefining Success</i></p>	<ul style="list-style-type: none"> ▪ As a result of the CoP, ODP is currently developing meaningful measures and outcomes.