



National Community of Practice for Supporting Families Evaluation

Annual Report 2018-2019

*Prepared for: Administration for Community Living
Office for Performance and Evaluation*

*Submitted by: New Editions
The Lewin Group*

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Executive Summary

Introduction and Background

In 2012, the Administration for Community Living (ACL) funded a National Community of Practice for Supporting Families (CoP) to build capacity across and within states to create policies, practices, and systems to better assist and support families that include a member with intellectual or developmental disabilities (I/DD) across the lifespan. ACL awarded a five-year grant to the National Association of State Directors of Developmental Disabilities Services (NASDDDS) in collaboration with the University of Missouri-Kansas City Institute on Human Development (UMKC-IHD) and the Human Services Research Institute (HRSI). NASDDDS selected five states to participate in the community of practice through a competitive application process: Connecticut, District of Columbia, Oklahoma, Tennessee, and Washington. Additionally, Missouri served as a demonstration state, due to its role in developing the Charting the LifeCourse (CtLC) framework.

As the grant period ended, ACL observed not only the success of the CoP participants, but growth of the CoP to include an additional ten states not affiliated with the grant. In 2017, ACL awarded an evaluation contract to New Editions Consulting and its partner, The Lewin Group, to evaluate the CoP.

Evaluation Design

Within its grant proposal, NASDDDS identified three project outcomes for the CoP.

Project Outcomes
➤ State and national consensus on a national framework and agenda for improving supports for families with children and adults 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

These outcomes continue to drive the work of the CoP, and this evaluation examines state and national progress towards meeting these outcomes. Results of the evaluation will:

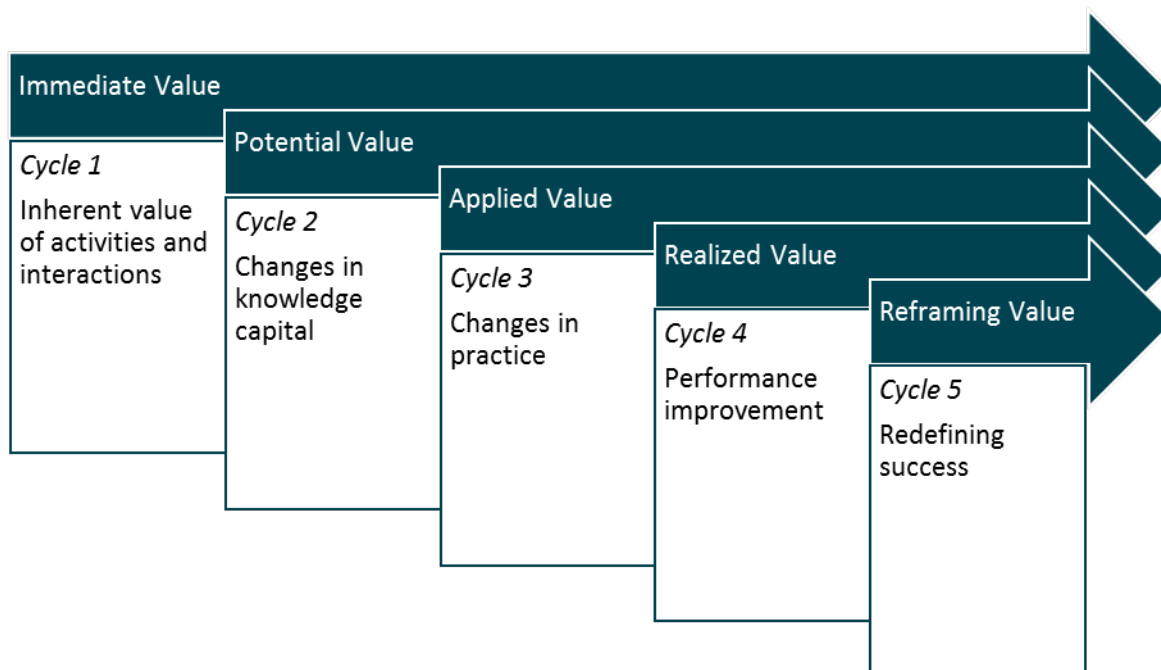
- Inform the Administration on Disabilities (AoD)¹ by providing outcomes data and recommendations to improve supports to families of individuals with I/DD, including the future application of the CtLC framework and CoP platform.
- Provide AoD with an updated systematic description of the range of CoP organizational structures, practices, and development across CoP states, which include consideration of the degree to which CoP states apply the principles and tools of the CtLC framework.

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

Methodology

The evaluation team adapted a framework developed by Wenger, Trayner, and de Laat² for promoting and assessing value creation in communities and networks (**Exhibit 1**). This framework assesses value creation across members, leaders, and partners of communities and networks. The framework allows the evaluation team to link specific activities of communities and networks with desired outcomes, while considering the value of the learning that involvement in those social networks facilitates.

Exhibit 1. Value Cycle Framework



All states that participated in the CoP for at least two years between 2012 and 2018 are included in the evaluation. The evaluation stratified states into three groups based on their stage of development (**Exhibit 2**).

Exhibit 2. Stratification of States by Group

Group	States
Group 1 Six original CoP states	<ul style="list-style-type: none"> ▪ Connecticut ▪ District of Columbia ▪ Missouri (mentor state) ▪ Oklahoma ▪ Tennessee ▪ Washington

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

Group	States
Group 2 Four expansion states with exposure to the CoP or CtLC framework prior to joining the CoP	<ul style="list-style-type: none"> ▪ Maryland ▪ Ohio ▪ Pennsylvania ▪ South Dakota
Group 3 Six expansion states with little or no prior exposure to the CoP or CtLC framework prior to joining the CoP	<ul style="list-style-type: none"> ▪ Alabama ▪ Delaware ▪ Hawaii ▪ Indiana ▪ Kansas ▪ Oregon

Data Collection Tools

The evaluation team developed a series of tools to collect data from states and the national project team (**Exhibit 3**). The evaluation team pilot-tested the reporting tools with two states and conducted modified cognitive testing to determine whether the tools performed as expected. The team revised the tools following the testing.

Exhibit 3. Data Collection

Data Collection Method	Description	Timeline
Reporting Tools	The team designed a reporting tool for each of the three groups of participants and loaded the tools into an online platform for states to complete. Each tool combined closed- and open-ended questions to document progress during the past year.	February 2019
Telephone Interviews	The evaluation team developed interview guides specific to each state based on the data submitted through the reporting tool. Guides included a core set of questions for each evaluation group.	March – April 2019
Site Visits	The evaluation team developed a site visit guide, which was adapted for each visit. The guides specified protocols for outreach, communication, planning, and documenting findings during the visit.	May – July 2019

Findings

After thorough analysis of the data collected through the reporting tools, telephone interviews, and site visits, several themes emerged related to each value cycle.

Cycle 1: Immediate Value

Value Cycle 1 evaluates the immediate value of state CoP activities to both members and the state. Activities that fall into this cycle have inherent value that may include information sharing, problem solving, peer-to-peer support, partnerships and collaboration, and listening to family voices. These activities may facilitate policy and practice changes in later cycles, which can contribute to improved supports and individual outcomes.

Cycle 1: Key Themes

- Stakeholders share information and support
- States derive benefit from their CoP structures and processes including increased connections with one another and peer-to-peer supports
- Family members and self-advocates inform needed services and supports, system processes, and policy
- Diverse partners engage around a shared purpose, generating buy-in and promoting collaboration across different systems

Cycle 2: Potential Value

Value Cycle 2 examines CoP activities and outputs expected to produce value in later cycles. This may include using the CtLC framework and tools, trainings or informational sessions, creating and disseminating products, identifying innovation areas, advancing current initiatives, changing thinking or knowledge, and more. Such changes in knowledge capital may lead to changes in practice.

Cycle 2: Key Themes

- Members' use and diffusion of the CtLC framework advances consensus
- States deploy diverse strategies to build knowledge
- States target new and existing initiatives for change
- Knowledge building leads to new ways of thinking

Cycle 3: Applied Value

Applied value examines the ways in which knowledge leads to innovation and change. In particular, Value Cycle 3 examines how state CoPs changed systems or practices to improve performance. This may include changes to policy (e.g., new waivers, new waiver services, and new legislation), changes to programs or services, revision to ISPs or other processes, developing new initiatives, creating new positions to meet a particular need, and measuring or monitoring services.

Cycle 3: Key Themes

- States change policies and services to advance supports to families
- States revise forms and processes to align with the CtLC framework

Cycle 4: Realized Value

Realized value refers to the effects of new practices that occur during Value Cycle 3. Impacts may include decreased reliance on formal services, reduced waiting lists and process times, changed behavior, increased access and efficiency in navigating systems, greater satisfaction, and better lives.

Cycle 4: Key Themes

- Stakeholders including CoP members, state service systems staff, families, and self-advocates behave in new and different ways
- State service systems operate more efficiently

Cycle 5: Reframing Value

In Value Cycle 5, prior changes in knowledge capital and practice lead to redefining success. Examples include measuring outcomes in new ways, and changing goals, strategies, or system operations because of the CoP. This cycle includes strategies for sustainability and how states redefined or revised their use of the CtLC framework.

Cycle 5: Key Themes

- State CoPs advance new goals, strategies, and operations
- State CoPs measure outcomes in new ways

Conclusion and Recommendations

The evaluation team identified a series of recommendations to inform ACL on future grants.

- Leverage the CoP platform in other systems change projects.
- Require strategic partnerships that can influence change at systems and grassroots levels.
- Identify clear performance measures for grantees.
- Support strategies for virtual engagement of grantees and states.
- Identify and model sustainability practices.
- Explore strategies to promote and incentivize evaluation participation after grant funding ends.

Introduction and Background

In 2012, the Administration on Disabilities (AoD) within the Administration for Community Living (ACL) funded a National Community of Practice for Supporting Families (CoP) to build capacity across and within states to create policies, practices, and systems to better assist and support families that include a member with intellectual and developmental disabilities (I/DD) across the lifespan. As the grant period ended, ACL observed not only the success of the CoP participants, but growth of the CoP to include an additional ten states not affiliated with the grant. In 2017, ACL awarded an evaluation contract to New Editions Consulting (New Editions) and its partner, The Lewin Group (Lewin) to identify how participating states are achieving project outcomes. In the 2017-2018 evaluation year, the evaluation team, comprised of New Editions and Lewin, developed the evaluation design based on a comprehensive environmental scan including stakeholder input. The Lewin Group led the implementation of the evaluation during the 2018-2019 evaluation year. This report documents findings from the first year of data collection.

National Community of Practice for Supporting Families

Wingspread Report

In 2011, leaders in the disability field came together at the Wingspread Summit to develop policy recommendations to improve supports to families with a member with I/DD. The Wingspread Summit produced a report that outlines recommendations, ensuring that people with I/DD are fully integrated and included in society, and recognizing the critical role of families in their lives. The U.S. Administration on Disabilities (AoD)³ used these recommendations to fund projects that year, including a request for proposal for what became the CoP.⁴

Wingspread Summit Report Recommendations

- Design the structure and functions of state service systems to include a focus on supporting families reflective of the fact that most people with I/DD are living with their families in the community.
- Develop and fund the National Supporting the Family Initiatives (now the CoP) which explores principles, practices, and data indicators used to inform practice and policy related to supporting families across the lifespan.
- Develop the National Data Collection Initiative (now the Family Information Systems Project) which contains consistent and uniform data, identifying the impact on families and people with I/DD and cost-effectiveness of supporting families across the lifespan.
- Increase recognition of the family's role in developing key federal policies and national programs.

Community of Practice Development

AoD awarded a five-year grant (2012-2017) to the National Association of State Directors of Developmental Disabilities Services (NASDDDS). NASDDDS collaborated with the University of Missouri-Kansas City Institute on Human Development (UMKC-IHD) and the Human Services Research Institute (HRSI) to form a national project team. The objective of this team, established

³ The Administration on Intellectual and Developmental Disabilities (AIDD) awarded funding to the CoP. The Administration on Disabilities (AoD) now oversees the evaluation of the CoP.

⁴ National Association of State Directors of Developmental Disabilities Services. (2017). Setting a Fresh Course: Assessing the Impact of the National Community of Practice for Supporting Families of Individuals with Intellectual and Developmental Disabilities. Final Report.

in October 2012, was to “build capacity across and within states to create policies, practices, and systems to better assist and support families that include a member with I/DD across the lifespan.” The goal of supporting families, as defined by the CoP, is to “best support, nurture, love, and facilitate opportunities for the achievement of self-determination, interdependence, productivity, integration, and inclusion in all facets of community life for their family members.”⁵

NASDDDS sought states to participate in the CoP through a competitive application process. Fifteen states applied and the national project team selected five states to participate: Connecticut, District of Columbia, Oklahoma, Tennessee, and Washington. Additionally, Missouri served as a demonstration state due to its role in developing the Charting the LifeCourse (CtLC) framework.

Evolution of the Charting the LifeCourse Framework

The CtLC framework helps individuals and families develop a vision for a good life, think about their options, identity and find supports, and discover how they can live their best life. The CtLC framework is comprised of a set of principles that support the core belief that “all people have the right to live, love, work, and play and pursue their dreams in their community.”⁶ This belief drives the work of CoP states on supporting families.

CtLC Principle	Description
ALL People	ALL individuals and families are considered in the CoP’s vision, values, policies and practices for supporting people with I/DD
People within the Context of Family and Community	Individuals and families need supports that address all life stages as family member roles and needs change over time.
Strategies to Support Families	Supports address all facets of life and include discovery and navigation (information, education, skill building), connecting and networking (peer support), and goods and services (daily living and financial supports).
Quality of Life Domains and Outcomes	Support structures that focus on self-determination, community living, social capital and economic sufficiency help plan for life outcomes, not just services.
Life Stages and Trajectory	Individuals and families can focus on a specific life stage, understanding how past, current, and future life stages will impact their life trajectory.
Integrated Delivery of Supports	Individuals and families can utilize a variety of integrated supports, including those that are publicly or privately funded and based on eligibility, available to anyone in the community, and relationship-based.

Initially called the LifeCourse Framework, the CtLC framework is rooted in various theories and concepts from the disability field, which include the notion of self-determination, family systems theory, person-and-family centered care, and other various models of disability. The CtLC

⁵ This definition is adapted from the Wingspread Final Report: Hecht, E., Reynolds, M., Agosta, J., & McGinley, K. (2011). Building an agenda for supporting families with a member with intellectual and developmental disabilities. Report of the Wingspread Conference on building a family support agenda, March 6-8, 2011. Racine, Wisconsin: Johnson Foundation.

⁶ <https://www.lifecoursetools.com/>

framework evolved throughout the course of the five-year CoP grant, and the model continues to develop based on the experiences of its users.

Evaluation Purpose and Goals

Within its grant proposal, NASDDDS identified three project outcomes for the CoP.

Project Outcomes
➤ State and national consensus on a national framework and agenda for improving supports for families with children and adults 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

These outcomes continue to drive the work of the CoP, and this evaluation examines state and national progress towards meeting these outcomes. Results of the evaluation will:

- Inform AoD by providing outcomes data and recommendations to improve supports to families of individuals with I/DD, including potential future application of the CtLC framework and CoP platform.
- Provide AoD with an updated systematic description of the range of CoP structures, practices, and development across CoP states, which include consideration of the degree to which CoP states apply the principles and tools of the CtLC framework.

Methodology

Evaluation Design

Evaluation Activities

The evaluation team engaged in a series of activities during the 2017-2018 evaluation cycle to inform the design of the evaluation.

- **Environmental scan and white papers.** The evaluation team conducted an environmental scan to provide ACL with a comprehensive review of the types of supports available to families of individuals with I/DD. This environmental scan informed two white papers. The first white paper summarized best practices in supports to families, components of the CtLC framework, and CoP state implementation of the framework. The second white paper included CoP state findings from telephone interviews, site visits, and attendance at the Annual CoP Meeting and CtLC Showcase, as well as materials obtained from these events.
- **Telephone interviews.** The evaluation team conducted individual and group telephone interviews with all CoP states to understand their organizational structure, goals, challenges, activities, and innovations.
- **Technical expert panels.** The evaluation team convened two technical expert panels to inform the design, implementation, and interpretation of findings.

- **Subject matter experts.** New Editions engaged industry leaders with professional and lived expertise, and experience in programs serving individuals with I/DD and their families in home and community-based settings.
- **NASDDDS and UMKC-IHD.** Experts from NASDDDS and UMKC-IHD guided the development of the CoP evaluation and its subsequent expansion.
- **Site Visits.** The evaluation team conducted site visits to selected states to gain an understanding of the activities and outcomes reported by states, in addition to interviewing state leadership teams, providers and case managers, intake and outreach staff, and families and self-advocates.
- **Annual CoP Meeting and CtLC Showcase.** The evaluation team attended the Annual CoP Meeting and CtLC Showcase in Kansas City, Missouri from April 18-20, 2018.

Evaluation Questions

There are several evaluation questions that directly correspond with the three project outcomes established by the CoP (**Exhibit 1**).

Exhibit 1. Project Objectives and Corresponding Evaluation Questions

Project Outcomes	Evaluation Questions
<p>State and national consensus on a national framework and agenda for improving support for families with children with I/DD</p>	<ul style="list-style-type: none"> ▪ How, and to what extent, did the national and state CoPs achieve consensus on a national framework for supporting families? ▪ How, and to what extent, are state CoPs using the CtLC framework to enhance supports to families of individuals with I/DD?
<p>Enhanced state policies, practices, and sustainable systems that result in improved supports to families</p>	<ul style="list-style-type: none"> ▪ What components of the national and state CoPs contribute to enhanced state policies, practices, and systems, and to what extent? ▪ How, and to what extent, have the enhanced state policies, practices, and systems improved the supports available to families? ▪ How, and to what extent, have the lives of families of children with I/DD improved or changed as a result of the work of the CoP?
<p>Enhanced capacity of states to replicate and sustain exemplary practices to support families and systems</p>	<ul style="list-style-type: none"> ▪ How are exemplary practices defined, identified, and verified, and which were most likely to be replicated and sustained, and why? ▪ How, and to what extent, do state CoPs build capacity to sustain their work after formal affiliation with the CoP concludes? ▪ What secondary outcomes did state CoPs experience beyond the stated project outcomes (if any)?

Evaluation Framework

The evaluation team adapted a framework developed by Wegner, Trayner, and de Laat⁷ for promoting and assessing value creation in communities and networks. This framework assesses value creation across members, leaders, and partners of communities and networks. The framework allows the evaluation team to link specific activities of communities and networks with desired outcomes, while considering the value of the learning that involvement in those social networks facilitates. This conceptual framework considers five different cycles of value creation, which provide a context for organizing, understanding, and analyzing data. These five value creation cycles, adapted to evaluate the CoP, include:

- **Cycle 1: Immediate Value – Value of activities and interactions themselves.** The activities and interactions between members of the CoP have inherent value. The value to members may include problem solving, support, information sharing, collaboration, or mutual understanding. Activities in Cycle 1 are expected to strengthen relationships, encourage information and knowledge exchange, and improve communications among stakeholders.
- **Cycle 2: Potential Value – Changes in knowledge capital.** Activities that increase knowledge, such as developing products and conducting trainings, generate value that is not realized immediately. The evaluation team expects changes in knowledge capital to lead to changes in practice by establishing a consistent knowledge base and producing clarity on needed systems changes.
- **Cycle 3: Applied Value – Changes in practice.** Applied value examines the ways in which knowledge leads to innovation, new approaches, or changes in practice. In particular, Cycle 3 examines how state CoPs changed systems or practices with a particular focus on how and why those changes are expected to improve outcomes for people with I/DD and their families.
- **Cycle 4: Realized Value – Performance improvement.** Realized value refers to the effect of new practices that occurred during Cycle 3, such as improvements in performance that are meaningful to stakeholders. To capture Cycle 4 value, the team evaluated the impact of efforts made during earlier cycles that increased self-determination, interdependence, productivity, integration, and inclusion in all facets of community life for people with I/DD, as well as supports to families.
- **Cycle 5: Reframing Value – Redefining success.** In Cycle 5, learning leads to redefining success, such as new goals, strategies, and performance metrics. To capture Cycle 5 value, the evaluation team examined how states realigned their existing goals and strategies to better support families and people with I/DD, including strategies for sustainability.

Evaluation Participants

All states that participated in the CoP for at least two years between 2012 and 2018 are included in the evaluation. The evaluation stratified states into three groups based on their stage of development (**Exhibit 2**).

⁷ Wegner, 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. Retrieved from http://wenger-trayner.com/wp-content/uploads/2011/12/11-04-Wenger_Trainer_DeLaat_Value_creation.pdf.

Exhibit 2. Stratification of States by Group

Group	Description	States
Group 1	Six original CoP states	<ul style="list-style-type: none"> ▪ Connecticut ▪ District of Columbia ▪ Missouri (mentor state) ▪ Oklahoma ▪ Tennessee ▪ Washington
Group 2	Four expansion states with exposure to the CoP or CtLC framework prior to joining the CoP	<ul style="list-style-type: none"> ▪ Maryland ▪ Ohio ▪ Pennsylvania ▪ South Dakota
Group 3	Six expansion states with little or no prior exposure to the CoP or CtLC framework prior to joining the CoP	<ul style="list-style-type: none"> ▪ Alabama ▪ Delaware ▪ Hawaii ▪ Indiana ▪ Kansas ▪ Oregon

Data Collection

The evaluation team designed a series of tools to collect data from states and the national project team (**Exhibit 3**). The evaluation team pilot-tested the reporting tools with two states and conducted modified cognitive testing to determine whether the tool performed as expected. The team revised the tools following the testing.

Exhibit 3. Data Collection Tools

Data Collection Tool	Description	Timeline
Reporting Tools	The team designed a reporting tool for each of the three groups of participants and loaded the tools into an online platform for states to complete. Each tool combined closed- and open-ended questions to learn about progress during the past year. States submitted data in the reporting tool for their respective group using an online platform. The evaluation team provided the group-specific link and a document containing the questions from the tool to each state.	February 2019
Telephone Interview Guides	The evaluation team developed interview guides specific to each state based on the data submitted in the reporting tool. Guides included a core set of questions for each evaluation group. Using these guides, the evaluation team conducted one-hour interviews with each state CoP and the national project team.	March – May 2019
Site Visit Guides	The evaluation team developed a site visit guide, which was adapted to each visit. The guides specified protocols for outreach, communication, planning, and documenting findings during the visit. The evaluation team conducted seven in-person and virtual site visits. In consultation with the national project team and ACL, Lewin identified a sample of states that represented each of the three evaluation groups' diverse structures and approaches. To ease burden on states, the evaluation team aligned visits with existing stakeholder, technical assistance (TA), and planning meetings.	May – July 2019

Note: The evaluation team assessed the value of conducting materials review of documents from states (e.g., CoP meeting notes, products, and presentations) and determined to exclude it as a data collection method.

Lewin conducted visits with a representative sample of states participating in the CoP (**Exhibit 4**).

Exhibit 4. Lewin Conducted Seven Site Visits

State	Date	Meeting Title	In-Person	Virtual
Indiana	May 16 – 17, 2019	Annual TA Visit from National Project Team	✓	
District of Columbia	June 7, 2019	State CoP Meeting	✓	
Missouri	June 12, 2019	Family-to-Family / Stakeholder Meeting	✓	
South Dakota	June 24, 2019	State CoP Meeting		✓
Maryland	June 25 – 26, 2019	Annual TA Visit from National Project Team	✓	
Kansas	July 17, 2019	Monthly Statewide Planning Meeting		✓
Ohio	July 31, 2019	State CoP Meeting	✓	

Communication

The national project team (NASDDDS and UMKC-IHD) served in an advisory role to Lewin during the evaluation year through regular meetings on evaluation activities and their review of evaluation tools and products. Lewin communicated key evaluation activities to states through email, participation in TA calls hosted by the national project team, and a presentation at the Annual CoP Meeting in Kansas City, Missouri in April 2019. Lewin also engaged with states during attendance at the Annual CtLC Showcase after the Annual CoP Meeting in Kansas City, Missouri in May 2019.

Data Analysis

The evaluation team analyzed data collected through the reporting tools, telephone interviews, and site visits using qualitative methods (**Exhibit 5**).

Exhibit 5. Data Analysis Methods

Data Collection Tool	Description
Reporting Tools	After receiving submissions from all states, Lewin reviewed reporting tool data to ensure all submissions were complete. Lewin followed up with project teams that submitted incomplete responses to determine whether blank fields were intentional or oversights. Lewin provided the opportunity to submit additional data. Using ATLAS.ti, the evaluation team coded data by value creation cycle, then by descriptive code.
Telephone Interview Guides	With each team’s permission, Lewin recorded the telephone interviews and documented each call with notes. The evaluation team coded data by value cycle and descriptive code using ATLAS.ti.

Data Collection Tool	Description
Site Visit Guides	Lewin produced a summary for each site visit, documenting activities and discussions. The team manually coded these notes to identify themes by value cycle.

Findings

After thorough analysis of the data collected through the reporting tools, telephone interviews, and site visits, several themes emerged from each value cycle.

Cycle 1

Value Cycle 1 captures the immediate value of state CoP activities that may facilitate policy and practice changes in later cycles and contribute to improved supports and individual outcomes.

- Stakeholders share information and support.** The CoP serves as a conduit for information exchange. States commonly use the CoP to share information with stakeholders regarding progress towards goals, new activities and initiatives, community events, CtLC tools and resources, and strategies for supporting families. States emphasized the importance of streamlining information dissemination efforts to ensure that accurate information is reaching the public from trusted sources (e.g., select state agencies or LifeCourse Ambassadors). CoP members also use the CoP to connect with one another and provide peer-to-peer supports. Some states developed web-based platforms to facilitate networking and communications. Nationally, CoP states are also sharing information with other CoP states regarding promising practices and lessons learned.
- Family members and self-advocates guide the agenda.** Families and self-advocates are often a part of CoP leadership. Their voices and perspectives inform needed services and supports, system processes, and policy. Many family members are also LifeCourse Ambassadors who participate in CoP meetings, trainings, and quality improvement efforts.
- States derive benefit from their organizational structure and processes.** States have varying CoP structures. Some states maintain formal, top-down structures in which project leaders clearly define roles and responsibilities, goals, and activities for the CoP; other states use an informal, bottom-up structure in which change happens more organically in response to visionary leaders or grassroots support. In some states, executive state teams maintain a feedback loop to share information with regional or local CoPs, whereas other states have one state CoP team. States reported that commitment and engagement from the state developmental disabilities (DD) agency or the DD Council are contributing factors towards achieving CoP goals. On a national level, select states (including those the evaluation team visited) reported that meetings and technical assistance (TA) provided by the national project team greatly benefitted their state’s efforts, in addition to relationships developed with other CoP states.
- Diverse partners engage around a shared purpose.** States are developing strong partnerships with various organizations to generate buy-in and promote collaboration across different systems. Partners include family support organizations, advocacy organizations, health and human service providers, provider agencies, education systems, employment initiatives, aging departments, Vocational Rehabilitation, University Centers for Excellence in Developmental

Disabilities (UCEDDs), Protection and Advocacy Systems (P&As), and more. Many of the representatives from these organizations attend CoP meetings.



The Ohio CoP consistently shares information and resources on available statewide programs and different family support models. This encourages communication, learning, and collaboration among existing efforts across the state. Lead partner organizations include the Department of Developmental Disabilities (DODD), DD Council, and both University Centers for Excellence in Developmental Disabilities (UCEDDs). All partners use the CtLC framework in their policy and systems change work.



CoP leadership and CoP members in Delaware are engaged in all CoP activities. They participate in outreach events, meet with stakeholders to understand their needs, and disseminate information and resources. 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.

States engaged in a variety of activities that generated immediate value (**Exhibit 6**).

Exhibit 6. Value Cycle 1 Activities Reported by States

State		Sharing information	Peer-to-peer support	Partnership/ collaboration between organizations	Listening to family/ self-advocate perspectives	Connection to national CoP	State CoP structure	State agency leadership participation	CoP member engagement
Group 1	<i>Connecticut</i>	✓	✓	✓	✓		◆	✓	◆
	<i>District of Columbia</i>	✓	✓	✓	✓	✓	✓	✓	✓
	<i>Missouri</i>	✓	✓	✓	✓	◆	✓	✓	◆
	<i>Oklahoma</i>			✓					
	<i>Tennessee</i>	✓	✓	✓	✓	✓			
	<i>Washington</i>	✓		✓	✓		✓		✓
Group 2	<i>Maryland</i>	✓		✓	✓	✓	✓	✓	
	<i>Ohio</i>	✓	✓	✓	◆	✓	✓	✓	◆
	<i>Pennsylvania</i>	✓		✓	✓		✓	✓	◆
	<i>South Dakota</i>	✓		✓	✓		✓	✓	✓
Group 3	<i>Alabama</i>	✓		✓			✓		
	<i>Delaware</i>		✓	✓	✓		✓		✓
	<i>Hawaii</i>	✓	✓	✓	✓				
	<i>Indiana</i>			✓	◆	✓	✓	◆	◆
	<i>Kansas</i>	✓		✓	◆				
	<i>Oregon</i>	✓	✓	✓					

State	Sharing information	Peer-to-peer support	Partnership/ collaboration between organizations	Listening to family/ self-advocate perspectives	Connection to national CoP	State CoP structure	State agency leadership participation	CoP member engagement
Total number of states reporting each activity (out of 16)	13	8	16	10	5	10	7	4

✓ State reported this activity this evaluation year.

◆ State did not report this activity this evaluation year due to past CoP advancements in this area.

Cycle 2

Value Cycle 2 examines CoP activities and outputs, such as use of the CtLC framework and tools, trainings or information sessions, creating and disseminating products, identifying innovation areas, advancing current initiatives, and changes in thinking or knowledge that are expected to produce value in later cycles.

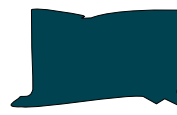
- Members’ use and diffusion of the CtLC framework advances consensus.** The CtLC framework is used both as an intervention to help individuals and families develop a vision for a good life, think about options, and identify supports, and to inform strategic reframing by helping systems and organizations prioritize strategies and evaluate activities. States are integrating the CtLC framework into front door interactions, trainings, transitions across the lifespan, individual service or support plans (ISPs) and other service planning processes, and strategic plans. Many states reported an existing Person Centered Thinking (PCT) foundation in their state, which the CtLC framework enhanced or supported. States emphasized the value of diffusing the CtLC framework and tools across sectors including health care financing, vocational rehabilitation, education, early childhood, mental health, behavioral health, employment, aging, housing, managed care, and case management.
- States deploy diverse strategies to build knowledge.** All CoP states conducted trainings on the CtLC framework. On a national level, CoP members completed the Ambassador Series and participate in the Annual CoP Meeting and CtLC Showcase. States commonly referenced the Ambassador Series as a key national training that helps support the spread and understanding of the CtLC framework. On the state level, trainings address utilization of the CtLC framework in areas such as technology and assistive technology, employment, self-determination, self-advocacy, case management, education, long-term support services, and planning services. State initiatives and trainings that incorporate the CtLC framework include Employment First, Partners in Policymaking, Youth Leadership Forum, and Person Centered Thinking (PCT) training. Audiences include individuals, families, support coordinators, case managers, intake and referral teams, personal support workers, providers, and staff in other state departments. Many CoPs also sponsor informal trainings or information sessions. To supplement ongoing training and education, many states have created and disseminated educational materials on the CtLC principles and tools. These materials apply CtLC to person centered practices,

employment, rights, planning, self-advocacy, self-direction, education, community supports, and more.

- **States target new and existing initiatives for change.** Every state CoP reported advancing current initiatives or goals to better support families in the past year. Primary goals and focus areas for state CoPs include:
 - Enhancing front door supports;
 - Including individuals and families in planning and implementation of services and supports;
 - Increasing the use of technology to support individuals with I/DD and families;
 - Advancing employment, post-secondary education, transition support, peer-to-peer support, capacity building, and supported decision making;
 - Implementing the Centers for Medicare & Medicaid Services (CMS) Home and Community Based Services (HCBS) Settings Final Rule;
 - Embedding CtLC in current practices; and,
 - Developing systems based recommendations.
 - Several states announced participation in new National Innovation Workgroups including Family and Self-Advocate Engagement, Cultural and Linguistic Competency, Implementation and Practice, and System Design and Quality.
- **Knowledge building leads to new ways of thinking.** States reported various ways in which the CoP or CtLC framework led to changes in thinking and knowledge. For example, the CtLC tools support families and self-advocates to consider alternative supports within the community before accessing state-funded services. The CtLC framework also helps professionals frame conversations using a common language, facilitates transitions throughout the lifespan, and contributes to an overall cultural shift among states.



South Dakota uses the CtLC framework in infrastructure and systems planning to provide a different lens towards progress. The CtLC framework is now working its way through several sectors within the state including Education, Department of Corrections, LTSS Systems, etc. The state CoP engages in informal CtLC training and education sessions with case managers, service coordinators, families, and self-advocates. South Dakota also created and disseminated the "Charting a Person-Centered Path to Employment" resource, which outlines services and provides anticipatory guidance.



Connecticut deploys diverse strategies to build knowledge. The 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). DDS also creates and disseminates a newsletter to families with CoP and CtLC information and resources.

States engaged in various activities to increase knowledge (**Exhibit 7**).

Exhibit 7. Value Cycle 2 Activities Reported by States

State		Using CtLC tools/principles	National training	State training	Informal training/education	Family outreach	Creating/disseminating products	Diffusion across sectors	Identifying innovation/focus areas	Advancing current initiatives/goals	Workgroup/learning community	Website/technology	Changes in thinking/knowledge
Group 1	Connecticut	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓
	District of Columbia	✓	✓	✓	✓	◆	✓	✓	✓	✓	✓	✓	✓
	Missouri	✓	✓	◆	✓	✓	✓	✓		✓	✓		✓
	Oklahoma	✓	✓	✓	✓		✓		✓	✓	✓		✓
	Tennessee	✓	✓	✓	✓		✓		✓	✓			✓
	Washington	◆		✓	✓			◆	✓	✓	✓	✓	✓
Group 2	Maryland	✓	✓	✓	✓	◆	✓	◆	✓	✓	✓		✓
	Ohio	✓	✓	✓	✓	◆	✓	✓	✓			✓	✓
	Pennsylvania	◆	◆	✓	✓	◆		✓	✓	✓	✓		✓
	South Dakota	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓
Group 3	Alabama	✓	✓	✓	✓	✓		✓	✓			✓	
	Delaware	✓		✓	✓	✓	✓		✓	✓	✓	✓	✓
	Hawaii	✓	✓	✓	✓	◆			✓	✓			✓
	Indiana	✓	✓	✓		✓		✓		✓	✓		✓
	Kansas	✓	◆	✓	✓			✓	✓				✓
	Oregon	✓	✓	✓	✓	✓		✓	✓	✓			✓
Total number of states reporting each activity (out of 16)		14	12	15	14	7	9	10	13	13	8	7	15

✓ State reported this activity this evaluation year.

◆ State did not report this activity this evaluation year due to past CoP advancements in this area.

Cycle 3

Applied value examines the ways in which knowledge leads to innovation, new approaches, or changes in practice, such as changes to policy (e.g., new waivers, new waiver services, and new legislation), changes to programs or services, revision to ISPs or other processes, new initiatives, creating new positions to meet a particular need, and measuring or monitoring services.

- States change policies and services to advance supports to families. Many states reported policy changes within the past year. Examples include the development and implementation of new waivers that embed the CtLC principles and language, new waiver services, passing the Technology and Employment First Act or other legislation, convening a Legislative Caucus on waiver waiting lists, and revising guidelines on eligibility or services offered. States noted the impact of the CMS HCBS Settings Final Rule in guiding other policy changes. States also use

the CtLC framework to change various programs and services, such as employment programs and grants, self-directed services, initiatives for preventing abuse, neglect, and exploitation, and assistive technology programs.

- **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 to inform intake and referral processes. Several states created new staffing positions to support collaboration within and between systems (e.g., service coordinators, family engagement director, community services director, employment director, and other liaisons). States reported increased skills of those who facilitate planning, transition, intake and referral, and case management to be more self-directed.



Oklahoma convened a Legislative Caucus that assured \$2 million in new money went towards Medicaid services for people on the waiting list.



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.



The District of Columbia enacted the Disability Services Reform Amendment Act of 2018 to improve the quality of life for people with I/DD by improving the complaint process, assuring no new people are committed, and enhancing supported decision making.

States engaged in a variety of specific activities to change policy and practice (**Exhibit 8**).

Exhibit 8. Value Cycle 3 Activities Reported by States

State		Change to policy	Change to program/services	Change in use of services	Revision to ISP or other forms/processes	Embedded CtLC principles/tools into operations	New initiatives	Aligning with other initiatives	Changes to recruitment/hiring practices	New staffing position created	Improved skills/capabilities of staff	Measuring/monitoring services
Group 1	<i>Connecticut</i>	✓	✓	✓	✓	✓	✓	✓		✓		✓
	<i>District of Columbia</i>	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓
	<i>Missouri</i>	✓			✓	✓	✓	✓		✓		
	<i>Oklahoma</i>	✓				✓				✓	✓	
	<i>Tennessee</i>				✓	✓						✓
	<i>Washington</i>	✓		✓				✓				✓

State		Change to policy	Change to program/services	Change in use of services	Revision to ISP or other forms/processes	Embedded CtLC principles/tools into operations	New initiatives	Aligning with other initiatives	Changes to recruitment/hiring practices	New staffing position created	Improved skills/capabilities of staff	Measuring/monitoring services
Group 2	Maryland	✓	✓		✓	✓	✓		✓	✓	✓	✓
	Ohio	✓	✓		✓	✓					✓	
	Pennsylvania	✓	✓	✓		✓	✓					✓
	South Dakota	✓	✓	✓	✓	✓	✓			✓	✓	✓
Group 3	Alabama		✓				✓	✓			✓	✓
	Delaware	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓
	Hawaii				✓	✓						✓
	Indiana	✓			✓	◆				◆		✓
	Kansas		✓			✓						
	Oregon	✓	✓		✓	✓						✓
Total number of states reporting each activity (out of 16)		12	10	6	11	13	7	5	1	7	7	12

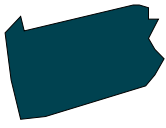
✓ State reported this activity this evaluation year.

◆ State did not report this activity this evaluation year due to past CoP advancements in this area.

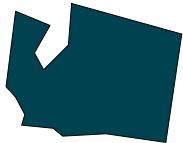
Cycle 4

Realized value refers to the effects of new practices that occur during Value Cycle 3. Impacts may include decreased reliance on formal services, reduced waiting lists and process times, changed behavior, increased access and efficiency navigating systems, increased satisfaction, and better lives.

- People behave in new and different ways.** States reported increased involvement by families in leadership and planning processes. States also identified a deeper understanding by families that the CtLC framework can produce real change, both individually and within systems. During site visits, many stakeholders shared how the CtLC framework influenced changes in their behavior, both in their professional and personal lives. For example, the CtLC framework helped stakeholders to focus more holistically. They no longer focus only on formal services, but what they can do to support people's lives.
- State service systems operate more efficiently.** More people are receiving community-based services and are having increased efficiency in accessing them. Additionally, states reported reductions in waiting list and processing times due to changes in policy.



Pennsylvania’s Employment First Act of 2018 expanded employment opportunities for individuals with disabilities. Over the last two years, Pennsylvania increased the proportion of the population of people with I/DD with competitive employment from 12% to 16%. Additionally, Pennsylvania modified eligibility criteria for three waivers, allowing individuals with autism spectrum disorder to transfer to self-directed care and other services. Individuals with autism spectrum disorder can now access services they previously could not. Pennsylvania identified these outcomes as a direct result of the ALL principle within the CtLC framework.



In Washington State, the Individual and Family Services Waiver allowed the state to bring 5,000 more people into services, an outcome that Washington State identified as directly influenced by CoP work. Additionally, Washington State held trainings on the community engagement service offered by the waiver, after which the number of people using that service rose from 20 to 900.

The evaluation team identified a series of activities related to realized value (**Exhibit 9**).

Exhibit 9. Value Cycle 4 Activities Reported by States

State		Less reliance on formal services	Reduction in waiting list/process times	New skills for using services/ supports	Changed behavior	Better experience with services/ systems navigation	Increased access/ efficiency	Increased satisfaction/ better lives
Group 1	Connecticut	✓					✓	
	District of Columbia		✓				✓	✓
	Missouri				◆			◆
	Oklahoma		✓				✓	✓
	Tennessee				✓			
	Washington				✓	✓	✓	✓
Group 2	Maryland		✓				✓	✓
	Ohio				✓			
	Pennsylvania				✓		✓	
	South Dakota		✓		✓			✓
Group 3	Alabama							
	Delaware	✓			✓		✓	✓
	Hawaii							
	Indiana				◆	◆		◆
	Kansas	✓				✓		
	Oregon			✓		✓		
Total number of states reporting each activity (out of 16)		3	4	1	6	3	7	6

✓ State reported this activity this evaluation year.

◆ State did not report this activity this evaluation year due to past CoP advancements in this area.

Cycle 5

In Value Cycle 5, changes in knowledge capital and practice lead to redefining success, such as measuring outcomes in new ways, and changing goals, strategies, or system operations because of the CoP. This cycle includes strategies for sustainability and how states redefined or revised their use of the CtLC framework.

- **State CoPs advance new goals, strategies, and operations.** States have aligned their state DD quality outcomes with the CtLC framework, and embedded it into scopes of work, strategic plans, and evaluation methods. States have significantly changed how their state DD agency approaches families and business practices, and always steer people to consider community resources first. Other states that initially focused on serving adults now target individuals at a younger age and now look at both the family and individual instead of the individual only.
- **States measure outcomes in new ways.** Several states changed goals, strategies, or systems operations as a result of the CoP or CtLC framework and some are also measuring and monitoring outcomes in new ways. For example, Oregon embedded the CtLC framework into the scope of work and evaluation methods required of Family/Peer Support Contractors (OCFN) in order to better articulate the intent of those contracts and expected outcomes.



In Maryland, local CoP leaders voiced that organizational decisions were often made by the national or state teams and trickled down without consulting others. State CoP leadership realized the need for a change in strategy and brainstormed ways to better include local CoP input, such as new circular pipelines of information between the state and local groups, a regular TA call, and the instatement of sharing and strategizing meetings. The emergence of these concerns created the potential for CoP reorganization to further benefit and include stakeholders.

Fewer states have reframed value as a result of the CoP because they are still progressing towards sustainable change. **Exhibit 10** documents key state activities.

Exhibit 10. Value Cycle 5 Activities Reported by States

State		Measuring outcomes in new ways as a result of the CoP	Changes in goals/strategies/system operations as a result of the CoP
Group 1	<i>Connecticut</i>		
	<i>District of Columbia</i>		✓
	<i>Missouri</i>	✓	✓
	<i>Oklahoma</i>		✓
	<i>Tennessee</i>	✓	
	<i>Washington</i>	✓	✓
Group 2	<i>Maryland</i>		✓
	<i>Ohio</i>		✓
	<i>Pennsylvania</i>	✓	
	<i>South Dakota</i>		✓
Group 3	<i>Alabama</i>		✓
	<i>Delaware</i>		✓
	<i>Hawaii</i>		✓
	<i>Indiana</i>	✓	
	<i>Kansas</i>		✓
	<i>Oregon</i>	✓	✓
Total number of states reporting each activity (out of 16)		6	12

✓ State reported this activity this evaluation year.

◆ State did not report this activity this evaluation year due to past CoP advancements in this area.

Conclusion and Recommendations

Evaluation Limitations

The evaluation team acknowledges several limitations of this study.

- Retrospective data collection.** Data collected during this evaluation year required participants to recall earlier activities and events. While the reporting tools focused on activities within the prior year, interview questions sometimes required participants to recall prior activities. Therefore, there may be some limitations in the accuracy and/or completeness of data.
- Post-grant evaluation.** ACL initiated this evaluation after the grant to NASDDDS ended. States' continued participation in the CoP is voluntary and self-funded. Given this context, the evaluation team designed the evaluation to minimize burden and collaborated with the national

project team to engage states and communicate value. The goal of being parsimonious may result in omitting important data points.

- **Evolution of national framework.** Achieving state and national consensus on a framework for supporting families is an outcome of the CoP. The CtLC framework is widely used and accepted as this national framework. CtLC evolved during the course of the grant period and continues to grow. States used the framework at various stages of its implementation, and measures of fidelity for the framework have not yet been established. A snapshot evaluation fails to capture the nuances of an evolving program.

Recommendations

The evaluation team identified a series of recommendations to inform ACL on future grants.

- **Leverage the CoP platform in other systems change projects.** The evaluation team observed both immediate value in the use of the CoP platform (e.g., access to information and support, engagement of diverse partners) and long-term value in states' ability to leverage the platform to achieve systems change (e.g., changing policies and services to advance supports to families). These findings suggest that the CoP platform could be effective in convening stakeholders to effect systems change on other topics of interest.
- **Require strategic partnerships.** Stakeholder partnerships, including engagement of self-advocates, are a frequent requirement of projects of national significance (PNS), such as the CoP. Unique to the CoP is the requirement that state teams include both the state DD agency and DD council. This reflects the national project team's emphasis on addressing supports to families through both personal and system perspectives. The evaluation team recommends incorporating specific expectations for strategic partnerships into future grant opportunities.
- **Identify clear performance measures for grantees.** The CoP provided states with flexibility to address the issues most pressing to their unique context. States consistently noted challenges related to quantifying and measuring their progress toward desired outcomes. The evaluation team recommends developing clear performance measures that are broad enough to account for variations among states, but specific enough for states to measure and report on progress both individually and collectively.
- **Support strategies for virtual engagement of grantees and states.** While face-to-face stakeholder engagement is usually ideal, the time and cost of attending regular in-person meetings can be prohibitive. This is particularly salient when stakeholders also have family caregiving responsibilities. Many CoP states explored virtual options for communicating with and convening stakeholders including conference calls, virtual meeting platforms (e.g., Zoom, Skype), and social media (e.g., Facebook). The evaluation team recommends additional TA on future projects to support and enhance states' ability to engage with stakeholders virtually.
- **Identify and model sustainability practices.** At the end of the grant, NASDDDS not only sustained the CoP with participating states, but expanded to include additional states. During this evaluation cycle, NASDDDS invited a third cohort of state to join the CoP. The evaluation team recommends documenting best practices related to the sustainability of this initiative for use on future projects.

- **Explore strategies to promote and incentivize evaluation participation after grant funding ends.** States' continued participation in the CoP is voluntary and self-funded. Their participation in the evaluation is also voluntary and may be burdensome in terms of time and effort spent on data collection activities. The evaluation team recommends the exploration of various incentive strategies to promote states' willingness to continue participating in the evaluation.

Next Steps

The evaluation team will continue to collect and analyze additional data during the 2019-2020 evaluation cycle.

Appendix

Appendix A: Data Collection Activities Timeline

The evaluation team collected data between February and July 2019.

Evaluation Tool	Dates for Data Collection	Feb 2019	Mar 2019	Apr 2019	May 2019	Jun 2019	Jul 2019
Reporting Tools	2/4/2019-3/1/2019	✓	✓				
Telephone Interviews	3/25/2019-5/15/2019		✓	✓	✓		
Site Visits	5/16/2019-7/31/2019				✓	✓	✓

Appendix B: Reporting Tool Survey for Groups 1-3

Purpose

This reporting tool is designed to collect information from each state on CoP structure and members, use of the CtLC framework, and improvements made to family supports. Information regarding changes made to policies, programs and services, and initiatives, as well as the impact or anticipated impact of these changes will also be captured. The information collected will be used to inform specific questions asked during telephone interviews. This version of the reporting tool is tailored to **Group 1** states, which include the six original CoP states (CT, DC, MO, OK, TN, and WA). All states are asked to complete the reporting tool one time this evaluation year with a time commitment of less than two hours.

Instructions

1. Please complete each question to the best of your abilities and based on your understanding of the question in context of your state. Additionally, please complete each question in the order that they appear (Note: The online tool contains skip logic, which may change the numbering of the questions from what is seen in this document). Questions may be in the format of multiple choice, check boxes, fill-in-the-blank, or descriptive narrative.
2. Please submit your responses using the [following Research.Net link](#). This Word document contains all questions asked through *Research.Net* and can be shared among respondents to prepare their responses.
3. These questions are to be completed by CoP facilitators and/or members of the CoP leadership team in your state that oversee day-to-day CoP activities. If you do not know the answer to a certain question, please inquire with a colleague who knows the answer. If this is not possible or your state does not have any activity to report in a particular area, please leave that field blank. Since states are focusing their efforts in different areas, it is expected that you will not have a response to every field.

Note: When we refer to the word “state” within this document, we are referring to all of the activities that occur within your state. We are not referring specifically to state-funded activities or activities for which a state agency is responsible.

If you have any questions, please email the evaluation team at Natalie.Boonchaisri@Lewin.com.

Reporting Tool Questions

1. CoP Structure and Members

- a. List the name, title, and email address of individual(s) responsible as the CoP point(s) of contact in your state. These are the individuals with whom the evaluation team will communicate. You may enter up to three individuals.
 - Contact 1 Name: _____
 - Contact 1 Title: _____
 - Contact 1 Email Address: _____
 - Contact 2 Name: _____

- Contact 2 Title: _____
 - Contact 2 Email Address: _____
 - Contact 3 Name: _____
 - Contact 3 Title: _____
 - Contact 3 Email Address: _____
- b. Do the individual(s) responsible as the CoP point(s) of contact in your state also rely on others for leadership, administration, and/or oversight of the CoP? We refer to these individuals as CoP leadership. Please select yes or no and complete the accompanying questions, if any.
- Yes [move forward to question 1c]
 No [skip question 1c and begin at question 1d]
- c. Identify the various roles of the individuals who participated in CoP leadership within the last year. As a reminder, CoP leadership refers to the individuals that the CoP point(s) of contact in your state also rely on for leadership, administration, and/or oversight of the CoP. Select all that apply.
- Self-Advocates
 Family Members
 Professional – Advocacy Organization
 Professional – State Agency
 Professional – Service Provider/Case Management
 Professional – Developmental Disabilities (DD) Council
 Professional – University Center for Excellence in Developmental Disabilities (UCEDD)
 Professional – State Protection & Advocacy System (P&A)
 Other, please specify: _____
- d. How many individuals comprise the CoP leadership in your state? As a reminder, **CoP leadership** refers to the individuals that the CoP point(s) of contact in your state also rely on for leadership, administration, and/or oversight of the CoP. Select one.
- 1-2 individuals
 3 individuals or more
 Not applicable
- e. Did CoP leadership perform any of the following activities in the last year? As a reminder, **CoP leadership** refers to the individuals that the CoP point(s) of contact in your state also rely on for leadership, administration, and/or oversight of the CoP. Select all that apply.
- Develop/facilitate training
 Identify/review CoP outcomes
 Review consumer satisfaction information
 Facilitate cross-agency/organizational meetings
 Build/maintain relationships
 Engage community resources
 Facilitate networking
 Support communication

- Identify/secure needed resources
 - Initiate partnerships
 - Other, please specify: _____
 - Not applicable
- f. How are individuals with I/DD currently engaged in CoP leadership? As a reminder, **CoP leadership** refers to the individuals that the CoP point(s) of contact in your state also rely on for leadership, administration, and/or oversight of the CoP. Select all that apply.
- Active CoP facilitator or leader
 - Active CoP member
 - Active CoP trainer
 - Advisor on policy development
 - Advisor on service and support development or implementation
 - Other, please specify: _____
 - Not applicable
- g. How are family members currently engaged in CoP leadership? As a reminder, **CoP leadership** refers to the individuals that the CoP point(s) of contact in your state also rely on for leadership, administration, and/or oversight of the CoP. Select all that apply.
- Active CoP facilitator or leader
 - Active CoP member
 - Active CoP trainer
 - Advisor on policy development
 - Advisor on service and support development or implementation
 - Other, please specify: _____
 - Not applicable

2. Improvements to Family Supports

- a. Did your CoP contribute to any of the following improvements or changes related to family supports in your state within the last year? Select all that apply. If no intended improvement or change was observed, but your state is actively working towards it, please select that field. If no intended improvement or change was observed and your state is not actively working towards it, please leave that field unchecked.
- Increased family member knowledge on how to better support their loved one(s)
 - Increased family member skills to navigate and access services
 - Enhanced family member ability to advocate for services and policy change
 - Increased family-to-family support
 - Increased self-advocacy
 - Increased use of non-disability community support
 - Increased access to self/family-directed services
 - Increased access to transportation
 - Increased access to respite/childcare
 - Increased access to/use of transition services

- Increased access to adaptive equipment
- Increased access to/use of technology by families or people with I/DD to promote independence and well-being
- Other, please specify: _____
- Not applicable

3. Impact of Partnerships

- a. As a result of your CoP activities, did partnerships (within or outside of the DD system) contribute to any of the following improvements or changes within the last year? Select all that apply. If no intended improvement or change was observed, but your state is actively working towards it, please select that field. If no intended improvement or change was observed and your state is not actively working towards it, please leave that field unchecked.
- Reduced fragmentation of services for individuals with I/DD
 - Improved system efficiency
 - Encouraged innovation
 - Increased collaboration
 - Maximized use of existing community assets
 - Other, please specify: _____
 - Not applicable [skip question 3b and begin at question 4a]
- b. Describe the impact or anticipated impact of the selected improvement(s) or change(s) resulting from partnerships on families and people with I/DD.

[The responses you selected from question 3a will carry over to this question]

4. Impact of Changes to Policies

- a. Did your CoP activities influence any of the following improvements or changes to STATE POLICY (e.g., law, regulation, executive order, or policy) within the last year? Select all that apply. If no intended improvement or change was observed, but your state is actively working towards it, please select that field. If no intended improvement or change was observed and your state is not actively working towards it, please leave that field unchecked.
- Reduced fragmentation of services for individuals with I/DD
 - Improved system efficiency
 - Encouraged innovation
 - Increased collaboration
 - Maximized use of existing community assets
 - Other, please specify: _____
 - Not applicable ***[skip question 4b and question 4c and begin at question 5a]***
- b. Describe the STATE POLICY (e.g., law, regulation, executive order, or policy) change that influenced or resulted in the selected improvement(s) or change(s) in your state within the last year.
- [The responses you selected from question 4a will carry over to this question]***
- c. Describe the impact or anticipated impact of the selected improvement(s) or change(s) resulting from STATE POLICY (e.g., law, regulation, executive order, or policy) change on

families and people with I/DD.

[The responses you selected from question 4a will carry over to this question]

5. Impact of Changes to Programs and Services

- a. Did your CoP activities influence any of the following improvements or changes to PROGRAMS and SERVICES within the last year? Select all that apply. If no intended improvement or change was observed, but your state is actively working towards it, please select that field. If no intended improvement or change was observed and your state is not actively working towards it, please leave that field unchecked.

Reduced fragmentation of services for individuals with I/DD

Improved system efficiency

Encouraged innovation

Increased collaboration

Maximized use of existing community assets

Other, please specify: _____

Not applicable ***[skip question 5b and question 5c and begin at question 6a]***

- b. Describe the PROGRAM and/or SERVICE change that influenced or resulted in the selected improvement(s) or change(s) in your state within the last year.

[The responses you selected from question 5a will carry over to this question]

- c. Describe the impact or anticipated impact of the selected improvement(s) or change(s) resulting from PROGRAM and/or SERVICE change on families and people with I/DD. ***[The responses you selected from question 5a will carry over to this question]***

6. Impact of Changes to Initiatives

- a. Did your CoP activities influence any of the following improvements or changes to EXISTING INITIATIVES or NEW INITIATIVES within the last year? Select all that apply. If no intended improvement or change was observed, but your state is actively working towards it, please select that field. If no intended improvement or change was observed and your state is not actively working towards it, please leave that field unchecked.

Reduced fragmentation of services for individuals with I/DD

Improved system efficiency

Encouraged innovation

Increased collaboration

Maximized use of existing community assets

Other, please specify: _____

Not applicable ***[skip question 6b and question 6c and begin at question 7a]***

- b. Describe the EXISTING INITIATIVE change(s) or NEW INITIATIVE(S) that influenced or resulted in the selected improvement(s) or change(s) in your state within the last year.

[The responses you selected from question 6a will carry over to this question]

- c. Describe the impact or anticipated impact of the selected improvement(s) or change(s) resulting from EXISTING INITIATIVE change(s) or NEW INITIATIVE(S) on families and people with I/DD.

[The responses you selected from question 6a will carry over to this question]

7. Progress towards AIDD Priority Areas

- a. Select the following Administration on Intellectual and Developmental Disabilities (AIDD) priority areas that your state progressed towards within the last year. Select all that apply. If your state did not progress towards a particular priority area, please leave that field unchecked. If your state focused elsewhere, please select not applicable.

- Protection of the rights of individuals with I/DD and preventing their abuse, neglect, and exploitation
- Individuals with I/DD and their families' ability to access home and community-based services and supports that are self-directed and ensure opportunity for full and meaningful community participation
- Participation of individuals with I/DD in the competitive, integrated workforce
- Participation of individuals with I/DD in system and service delivery design
- Better supporting families of individuals with I/DD
- Increasing systems' focus on community integration at all levels and stages of service from information and referral, needs assessments, service matching, and service provision
- Not applicable *[skip question 7b, question 7c, and question 7d and begin at question 8a]*

- b. Describe the specific goal(s) your CoP identified within the last year that align with the selected Administration on Intellectual and Developmental Disabilities (AIDD) priority areas.

[The responses you selected from question 7a will carry over to this question]

- c. For the goal(s) identified for each selected AIDD priority area, identify your state's current state of progress. ***[The responses you selected from question 7a will carry over to this question]***

- Not started
- In progress
- Achieved

- d. For the goal(s) identified for each selected AIDD priority area, briefly describe how progress towards this goal is being monitored in your state and what is being measured. If your state is not monitoring and/or measuring progress towards this goal, please leave that field blank.

[The responses you selected from question 7a will carry over to this question]

8. Use and Effect of CtLC Framework

- a. Indicate whether use of the Charting the LifeCourse (CtLC) framework in your state INFLUENCED any of the following improvements or changes within the last year. Select all that apply. If no improvement or change was observed, please leave that field unchecked.
- Increased number of people receiving services and supports from state-funded services
 - Increased number of people receiving services and supports from non-state-funded services
 - Expanded reach of services and supports geographically
 - Expanded reach of services and supports by population (e.g., new age groups)
 - New services available to support families
 - Improvements in existing services available to support families

- Improved process of accessing services (supported consumer navigation)
- Less time spent at front door/seeking services
- Shortened wait lists to receive services
- Improved connections between consumers and their communities
- Improved connections between agencies serving individuals with I/DD and their caregivers/families
- Increased access to goods and technologies to support life goals of individuals with I/DD
- Professional development of those who use the CtLC framework in their work
- Other, please specify: _____
- Not applicable *[skip question 8b and begin at question 9a]*

- b. For each selected improvement or change that was influenced by the Charting the LifeCourse (CtLC) framework, identify the degree to which the CtLC framework influenced the observed improvement or change. Please use the following definitions for high, medium, and low to identify the degree to which the CtLC framework influenced the observed improvement or change: *[The responses you selected from question 8a will carry over to this question]*
- High – The improvement or change likely would not occur without the influence of the CtLC framework.
 - Medium – The improvement or change likely would occur differently or to a lesser extent without the influence of the CtLC framework.
 - Low – The improvement or change likely would occur without the influence of the CtLC framework.
- c. If there is more you’d like to tell us about your state’s activities, please use the box below to provide us with any additional information.

9. Group-Specific Questions

Questions Specific to Group 1 States (CT, DC, MO, OK, TN, and WA)

- a. What actions have you taken in the last year to support sustainability of your CoP? Select all that apply.

- Formalized structures or processes associated with the CoP
- Enhanced or formalized leadership roles
- Strengthened or formed new partnerships
- Increased use or application of the CtLC framework or tools
- Increased involvement of families and self-advocates
- Increased community support
- Identified or secured sustainable funding
- Other, please specify: _____

Questions Specific to Group 2 States (MD, OH, PA, and SD)

a. Have you adopted practices in your state from other participants in the national CoP? Please select *yes* or *no* and complete the accompanying questions, if any.

- Yes ***[move forward to next question]***
- No ***[skip next question]***

b. Identify the various practices your state adopted from other participants in the national CoP. Select all that apply.

- Practices related to CoP structure (e.g., organizational structure, meeting schedule)
- Practices related to knowledge building and dissemination (e.g., products, tools, training)
- Practices related to policy change
- Practices related to program or service changes
- Practices related to engagement with families and/or self-advocates
- Other, please specify: _____

c. To the best of your knowledge, have other participants in the national CoP adopted practices from your state? Please select *yes* or *no* and complete the accompanying questions, if any.

- Yes ***[move forward to next question]***
- No ***[skip next question]***

d. Briefly describe the practice(s) that other participants in the national CoP adopted from your state.

e. Which of the following objectives did you intend to achieve in your state by joining the National Supporting Families Community of Practice? Select all that apply.

- Enhance supports to families
- Improve formal service and support programs for people with I/DD
- Improve informal supports for people with I/DD
- Increase engagement of family members and self-advocates in service delivery and/or policy development
- Increase partnerships and collaboration

- Increase use of the CtLC tools and framework
- Other, please specify: _____

- f. Identify the degree to which having previous exposure to the CtLC framework (before joining the expansion state cohort) in your state influenced your state’s ability to achieve outcomes.
- g. High – If my state did not have previous exposure to the CtLC framework (before joining the expansion state cohort), my state would not have achieved the outcomes we’ve achieved today.
- h. Medium – Having previous exposure to the CtLC framework (before joining the expansion state cohort) influenced my state’s ability to achieve outcomes, but to a lesser extent.
- i. Low – Having previous exposure to the CtLC framework (before joining the expansion state cohort) did not influence my state’s ability to achieve outcomes.

Questions Specific to Group 3 States (AL, DE, HI, IN, KS, and OR)

- a. To what degree did the opportunity to engage with other states through the national CoP help your state CoP to achieve or progress toward its goals within the last year?
- b. High – Engaging with other states was essential in achieving or progressing toward my state CoP’s goals within the last year.
- c. Medium – Engaging with other states was helpful in achieving or progressing toward some of my state CoP’s goals within the last year.
- d. Low – Engaging with other states did not affect my state CoP’s ability to achieve or progress toward goals within the last year.
- e. N/A – My state did not engage with other states within the last year.
- f. To what extent does your state CoP align with the CtLC framework as a national framework for supporting families?
- g. Fully – All of my state CoP activities are fully aligned with the CtLC framework.
- h. Partially – My state CoP activities are partially aligned with the CtLC framework.
- i. Little or not at all – My state CoP activities are minimally or not yet aligned with the CtLC framework.
- j. What contextual factors within your state have influenced your state CoP’s success? Select all that apply.
 - Existing experience with person-centered approaches
 - Existing partnerships
 - Meaningful engagement with families and self-advocates
 - Dedicated CoP leadership
 - Availability of funding for CoP activities and administration
 - Other, please specify: _____

Variations between groups 1-3

The states involved in the CoP were divided up into three groups for the purpose of the evaluation. This appendix refers to the reporting tools used with Group 1 states, which includes CT, DC, MO, OK, TN and WA. Group 2 includes states with exposure to the CtLC framework prior to joining

the expansion state cohort. Group 2 states include MD, OH, PA, and SD. Group 3 includes states with little or no exposure to the CtLC framework prior to joining the expansion state cohort. Group 3 states include AL, DE, HI, IN, KS, and OR. The reporting tool questions were kept consistent across all three state groupings.

Appendix C: Telephone Interview Guide

Purpose

This document will guide the telephone interview conducted with the state CoP team from each participating state, and should take one hour or less of time. Interview guides will be tailored to each state using data collected from the reporting tool. Facilitators will use this document as a guide to cover all necessary areas. Facilitators and note-takers should review each state's respective reporting tool prior to the interview.

Interview Script

Introduction

Introduce yourself and the note taker briefly with your names and role on the project. Ask for or state their name and job title/role in the CoP.

Thank you for your time today. In this conversation, we'll ask questions to get more narrative context for the data you shared through the reporting tool. We're interested to hear about your CoP and its activities directly from you. Today, we'll focus on connecting the dots between activities common across states, and progress towards outcomes you reported in the reporting tool, especially those affecting the AIDD priority areas.

For note taking purposes, we'd like to record this interview to be able to refer back to. Is your team comfortable with us doing so? *Wait for them to confirm.* Thank you. Do you have any questions before we get started?

1. First and foremost, we reviewed your reporting tool responses. Are there any recent changes, successes, or challenges within your CoP that you'd like to highlight for us before we get started?
2. There are several accomplishments noted in your reporting tool that we'd like to ask more about:
 - The section includes state specific prompts that are tailored to the data collected from the reporting tool data.
 - Example Prompt: Your state noted the launch of a new program that has embedded the CtLC framework into its structure/goals. Can you provide more details on this accomplishment?

Improvements/changes and the CtLC framework

We'd like to ask about the improvements/changes occurring in your state's CoP and your use of the CtLC framework.

1. You reported a number of improvements/changes in the reporting tool as a result of the CoP and/or the CtLC framework. [Reference a couple of examples from the reporting tool. List the specific performance improvements/changes noted by the state in the reporting tool.]
 - Ask the state to expand upon one specific performance improvement referenced above.

- i. Do you believe the reported improvements/changes would have occurred without influence of the CoP and/or CtLC framework?
 - ii. Without the CoP and/or CtLC framework, would it have taken longer or been more difficult to achieve these improvements/changes?
2. In the reporting tool, you indicated progress towards specific AIDD priority areas within the last year. I'd like to ask more about the activities that are contributing to your progress. *[Ask only about priority areas reported in the reporting tool]*
List several areas where progress has been made toward specific AIDD priority areas referenced by the state. Include whether the state has achieved this goal, or if they are still working towards completing it.
Ex. Individuals with I/DD and their families' ability to access home and community-based services and supports that are self-directed and ensure opportunity for full and meaningful community participation – in progress (Connecticut)
 - Include a state specific prompt that asks the state CoP team to identify the specific activities that led to the progress toward AIDD priority areas referenced above.
 - One of the initial goals of the project was to achieve state and national consensus on a national framework for support families. To what extent have you achieved consensus as a state and with the national CoP?

Sustainability

Let's move on to sustainability.

1. How would you describe your state CoP's strategy and ability to build capacity and sustain your efforts?
2. Are there any lessons learned or promising practices you would share with other states or organizations that led to the improvements/changes seen within your state?

Changes in Goals/Strategies

For our last topic, I'm going to ask about changes in goals and expectations.

1. Have you changed goals or strategies because of participation in the CoP? If yes, describe.
2. Have you changed the way you measure success because of participation in the CoP? If yes, how?
3. Have you seen any secondary or unexpected outcomes?

Wrap Up

1. Is there anything else you'd like to share today?
2. Do you have any questions before we end?

Thank you so much for participating today! This is incredibly valuable information that we will use to inform our evaluation findings. In the next few days, if you think of anything you wish you'd shared or asked, please reach us by email. As for next steps, we will soon conduct site visits to select states. If your state is selected, you will soon receive an email from a member of the evaluation team to determine if this is feasible. Thank you again, and have a great day!

Appendix D: Site Visit Guide

Purpose

This guide contains protocols for planning and implementing site visits with CoP states, including note-taking templates and questions to guide interviews with CoP leadership.

Lewin will conduct up to six site visits between May and mid-August on an annual basis. Selected site visit states will represent various levels of CoP participation, implementation, success, and geography across the U.S. During site visits in year one, Lewin will attend prescheduled CoP meetings, stakeholder meetings, TA visits conducted by NASDDDS, and/or trainings. During these meetings, Lewin will maintain the role of observers. If possible, Lewin will also hold a brief meeting with CoP leadership after the prescheduled meeting to discuss any remaining questions. This revised approach is intended to reduce evaluation activity burden on states.

Timeline

Exhibit 1 outlines the timeline for activities associated with each site visit counting from the first day of the site visit.

Exhibit 1. Site Visit Timeline

Timeframe	Action Item	Completion Date
1- 2 Months Prior	Contact the state point(s) of contact by email and request dates of their upcoming CoP meetings, stakeholder meetings, trainings, and/or TA visits	60 days before
	<ul style="list-style-type: none"> ▪ Request meeting with CoP leadership, time permitting ▪ Confirm site visit date(s), times, and locations ▪ Request agenda and list of attendees 	45 days before
	Develop site visit materials, including an agenda and adapted evaluation questions, and send to ACL one week prior to site visit	2 weeks before
Month of Site Visit	If meeting with CoP leadership is permitted, share adapted evaluation questions with the state point(s) of contact prior to the site visit	1 week before
	Conduct site visit	
	Develop site visit summary and share with ACL	1 week after

Scheduling

Initial Outreach

The evaluation team sent an email to all states on April 24, 2019 to inform them of the revised approach to site visits and that communication will be sent to select site visit states in the coming weeks. Email text is included in **Figures 2 and 3**.

Figure 2. Outreach Email Text to All States

From: Natalie Boonchaisri

To: Point(s) of Contact in All CoP States

Subject: ACL Supporting Families CoP Evaluation - Site Visits and Materials Review

Message:

Thank you for your time and participation in ACL's evaluation of the Supporting Families Community of Practice. We've enjoyed learning about your activities and achievements through completion of the reporting tool and telephone interviews to date, and we look forward to conducting the remaining telephone interviews. We hope to see many of you at the upcoming Annual CoP Meeting and Charting the LifeCourse Showcase next week.

The next step in the evaluation is to conduct site visits with up to six states. After hearing feedback from states, NASDDDS, and UMKC, our team is revising our approach to site visits. Instead of visiting the six original CoP states, we will select six states from the entire cohort of Supporting Families Community of Practice states. This will allow us to gather data from states representing various levels of CoP participation, approaches to implementation, and geography across the U.S. Additionally, in efforts to reduce state burden, we propose aligning our visits with existing activities, such as CoP meetings, stakeholder meetings, TA visits conducted by NASDDDS, and/or trainings. Site visits will take place over 1-2 days. If time permits, the evaluation team will request to schedule a brief meeting with CoP leadership to discuss any remaining questions.

We will be conducting the materials review on an ad hoc basis. Several of you have already supplied materials to enhance our understanding of state activities. We will reach out individually to request any additional materials based on your reporting tool and telephone interview responses.

We will communicate with states proposed for site visits in the coming weeks. If you have any questions, please email the evaluation team at Natalie.Boonchaisri@Lewin.com. We thank you in advance for your support in this evaluation.

Figure 3. Outreach Email Text to Select Site Visit States

From: Natalie Boonchaisri

To: Indiana, Missouri, Maryland, Ohio, Pennsylvania, and South Dakota

Subject: ACL Supporting Families CoP Evaluation - Site Visit Request

Message:

Thank you for your time and participation in ACL’s evaluation of the Supporting Families Community of Practice. It was great to see you at last week’s Annual CoP Meeting and Charting the LifeCourse Showcase in Kansas City, Missouri. The next step in the evaluation is to conduct site visits with up to six states. In efforts to reduce state burden, we propose to attend existing CoP meetings, stakeholder meetings, TA visits conducted by NASDDDS, and/or trainings. During these meetings, the evaluation team will maintain the role of observers.

Due to the unique activities occurring in [INSERT STATE NAME], the evaluation team concluded that a site visit to your state would help inform the evaluation. Are there any CoP meetings, stakeholder meetings, TA visits conducted by NASDDDS, and/or trainings happening in your state between now and mid-August that your team would welcome us to observe? If time permits, we would also like to have a brief 30-minute discussion with CoP leadership after the meeting to ask a few remaining questions. Please let us know if this is feasible and if you have any questions.

Follow Up

The evaluation team will follow up individually with select states to confirm upcoming meetings, request a brief meeting with CoP leadership during the visit, and identify relevant details, including time, location, attendees, and agenda.

Sample Agenda

Activity	Attendees	Location
CoP Meeting, Stakeholder Meeting, TA Visit, and/or Training	<ul style="list-style-type: none"> ▪ CoP Leadership ▪ Project Partners ▪ Stakeholders ▪ Lewin Project Manager (or designee) ▪ Lewin Task Coordinator 	TBD
Meeting with CoP Leadership	<ul style="list-style-type: none"> ▪ CoP Leadership ▪ Lewin Project Manager (or designee) ▪ Lewin Task Coordinator 	TBD

Site Visit Protocols

Evaluation Team Attendance and Roles

Two members of the evaluation team will conduct each site visit: (1) the project manager or designee; and (2) the task coordinator. Both members of the evaluation team will observe the identified meeting and take notes using the template in **Appendix A**. During meetings with CoP leadership, both evaluation team members will participate in active discussion and take notes using the template in **Appendix B**.

If requested by the state, team members will introduce themselves and briefly summarize their purpose for attending the identified meeting. Team members may respond to questions about the evaluation, if requested by the state. The evaluation team will not request time on the agenda to address the group, but will gladly provide updates if requested by the state.

Potential CoP Leadership Meeting Topics

The following prompts will guide discussion with CoP leadership, based on available time and relevancy to the specific state. Specific questions will be informed by telephone interview transcripts and responses to the reporting tool.

- Please share your reactions to the identified meeting. What are you pleased with? Do you have any areas of concern or challenges you anticipate? Did anything surprise you?
- What environmental or contextual factors (e.g., leadership, complying with HCBS final rule, waiver renewals, new director/staff) contributed to the achievements/successes seen in your state? How are you managing those factors?
- Please discuss any other challenges or barriers experienced in your state and strategies used to overcome those barriers. Additionally, please discuss any promising practices.
- *Optional:* Do you feel self-advocates and families have access to the supports needed to meaningfully engage in your CoP? Have you faced any challenges in your engagement of self-advocates and families, and have you identified any strategies for overcoming those challenges?
- *Optional:* Please discuss any progress toward project sustainability and/or any practices that are leading toward scalability or replicability of your model.
- *Optional:* Are there any other updates related to your CoP that we haven't discussed that you would like to share with the evaluation team?

Follow Up

Within a week of each site visit, the evaluation team will send an email to each state thanking them for the opportunity to visit and will submit a site visit summary to ACL.