Intellectual and Developmental Disabilities

The Community of Practice for Supporting Families of People with Intellectual and Developmental Disabilities
--Manuscript Draft--

Manuscript Number:	IDD-D-21-00020R2
Article Type:	Research
Keywords:	supporting families; intellectual and developmental disability; Charting the LifeCourse; community of practice
Corresponding Author:	Susan B. Palmer, Ph. D. University of Kansas Lawrence, Kansas UNITED STATES
First Author:	Michelle C. Reynolds, Ph. D
Order of Authors:	Michelle C. Reynolds, Ph. D
	Diana Caldwell, MSW
	Natalie Boonchaisri, MPH
	Katherine C. Ragon, MS
	Susan B. Palmer, Ph. D.
Manuscript Region of Origin:	UNITED STATES
Abstract:	It is important to continuously support families to improve the lives of people with intellectual and developmental disabilities (IDD) and their family members. Using a life course approach to address strengths and needs of families, a National Community of Practice, infused with the Charting the LifeCourse framework, focused on systems change to improve policy and practices to enhance the lives of families. A qualitative analysis used the Value Creation framework to evaluate both process and product outcomes of 16 state communities of practice as to changes in knowledge and practices. Results emphasize the relative effectiveness of aspects of policy and overarching practices designed to support people with disabilities and their families in participating states.

SUPPORTING FAMILIES CoP

The Community of Practice for Supporting Families of Persons with Intellectual and

Developmental Disabilities

Abstract

It is important to continuously support families to improve the lives of people with intellectual and developmental disabilities (IDD) and their family members. Using a life course approach to address strengths and needs of families, a National Community of Practice, infused with the *Charting the LifeCourse* framework, focused on systems change to improve policy and practices to enhance the lives of families. A qualitative analysis used the Value Creation framework to evaluate both process and product outcomes of 16 state communities of practice as to changes in knowledge and practices. Results emphasize the relative effectiveness of aspects of policy and overarching practices designed to support people with disabilities and their families in participating states.

Keywords: supporting families, intellectual and developmental disability, Charting the LifeCourse, community of practice

The Community of Practice for Supporting Families of Persons with Intellectual and

Developmental Disabilities

Current initiatives for supporting families are informed by activities, legislation, and evolving theories of disability as to how people with IDD and their families have been perceived over time. In the early 20th century, the perception of disability as difference prevailed (Brown et al., 2017). Medical professionals encouraged families to isolate their loved ones with disabilities in institutional or group settings (Turnbull & Turnbull, 2000). However, a change in theoretical orientation to viewing disability from a perspective of strength (Buntinx, 2013) is beginning to surpass the medical model of deficits to characterize disability in society. Within positive psychology, disability is seen from a lens of hope and opportunity rather than as pathology (Wehmeyer, 2013). Families may look to a system of supports and accommodations for their loved ones with disabilities, rather than focusing entirely on remediation (Reynolds et al., 2018).

One way to address wants and needs of individuals with IDD is through person-centered planning involving family or trusted members of the community as identified by the focus person with disabilities. Martin et al., (2016) view person-centered planning as an approach that redistributes power from service systems to individuals within families. However, families are often ignored even though families play a lead role in supporting members with disabilities (Reynolds et al., 2016). Thompson and Viriyangkura (2013) point out that community-based services over the past 50 years used structured programs that rarely promoted authentic person-centered planning for supporting people with IDD served in groups. A singular focus on people with IDD as individuals within policies, funding, and service delivery systems tends to overlook the role of families throughout the life course, especially concerning person-centered planning. Thus, the Centers for Medicare & Medicaid Services (CMS) final Home and Community-Based settings

rule (CMS, 2014) guides states using Medicaid-funded services to deliver these services in inclusive homes and communities, requiring person-centered planning informed by important people in the life of the person with IDD. However, not everyone with IDD receives formal supports.

Larson et al. (2020) estimated that of the 7.38 million people with IDD living in the US in 2017, only 20% (1.48 million) were known to or served by state disability services; little is known about the other 80% of people with IDD outside service systems. Approximately 60% of the 1.48 million people with IDD live in the family home (Larson et al., 2020). Weeks et al. (2009) identified that parents of aging adults said they worry about future care; funding for services, housing, and care options; lack of provider understanding of family caregivers' needs; and how to help their son or daughter with IDD be a productive and active member of society. This listing can also apply to the ongoing needs of families at different life stages.

A joint position statement of The Arc of the U.S. and American Association on Intellectual and Developmental Disabilities (AAIDD) both identifies desired outcomes for individuals with IDD and lists a range of family caregivers who support loved ones with IDD:

> Family support services and other means of supporting families across the lifespan should be available to all families to strengthen their capacities to support family members with intellectual and developmental disabilities (IDD) in achieving equal opportunity, independent living, full participation, and economic self-sufficiency. Family caregivers include, but are not limited to, parents (including those with IDD themselves), adoptive parents, foster parents, siblings, uncles, aunts, cousins, grandparents, grandchildren, and individuals who are in spousal-equivalent relationships (AAIDD, 2019).

There is a need to enhance policies and practices that support families with members with intellectual and developmental disabilities (IDD) across the life course (Grossman & Magaña, 2016). Our aim is to describe the key outcomes of a process and outcome evaluation of a nation-wide project using a multi-level Community of Practice (CoP) model (an overarching national CoP linking 16 state CoPs focused on state-wide initiatives) to bring about systems change in policy and practice of supporting families of people with IDD. The Wingspread consortium of practitioners, policy makers, persons with disabilities, and family members adopted the action-oriented phrase, "supporting families" to expand "family support" from a unidimensional service (Hecht et al., 2011). Supporting families involves fulfilling a broad spectrum of needs of families across the lifecourse within the national and state policies and state or regional practices.

The Community of Practice Model and Charting the LifeCourse Framework

  Community of Practice Model. The Administration for Community Living (ACL) specified using the structural model of CoP to address systems change in policy and practice in funding to the National Association of State Directors of Developmental Disabilities Services (NASDDDS), the University of Missouri-Kansas City's Institute for Human Development (UMKC-IHD), and the Human Services Research Institute (HSRI). A community of practice (CoP) is a participatory model in which people are involved in solving a set of problems related to a common concern or pursuing information to address a mutual topic of interest and engage in collaboration, learning, or knowledge generation (Cambridge et al., 2005). The national team at NASDDDS, UMKC, and HSRI infused a generic CoP model with the Charting the LifeCourse (CtLC; https://www.lifecoursetools.com/) framework (Reynolds et al. , 2012) to capture and refocus systems level change within state Developmental Disabilities (DD) agencies to expand a network of formal and informal initiatives for supporting families within states. The National

CoP both engaged states in an ongoing dialog about supporting families; provided a forum to share each state's successes and barriers to improvement, organized online forums on topics such as family involvement, employment, and policy change; and encouraged each state team of professionals, parents, and self-advocates to bring about systems change within states.

In preparation to build capacity within states to create policies, practices, and systems to better assist and support families of people with IDD, the national team focused on the three core characteristics of a CoP – Domain, Community, and Practice (Lewin, 2020). According to Wenger-Trayner & Wenger-Trayner (2015), members of CoPs must share a commitment to, and competency in a shared domain of interest (Domain), participate in the activities and build relationships to facilitate information sharing (Community), and display a shared practice through sustained interaction (Practice). The national team developed the CoP guided by a series of phases: 1) Inquire, 2) Design, 3) Prototype, 4) Launch, 5) Grow, and 6) Sustain (Cambridge et al., 2005) to address issues and pathways to supporting families. In preparation to begin the CoP, the national team determined the audience (state networks), focus (supporting families), purpose (create a community for social learning – sharing information, learning for the experiences of others, addressing challenges, knowledge creation, and addressing change; Wenger et al, 2011), goals (enhance policy and practice related to supporting families), and outcomes (defined as value stories that occur within CoPs; Wenger et al., 2011). Beyond providing a national structure for active engagement of all CoP members, the national team modeled support and accountability between overall systems and grassroots initiatives of families and self-advocates to engage in bi-directional sharing of promising practices, innovations, and implementation strategies to support families. No idea or practice was too insignificant to discuss, and all

partners in CoPs were encouraged to speak up and out in sharing ideas for both systems change and person- and family-centered planning.

Then, over time, in Design and Prototype phases, activities, technologies, and group processes evolved through use of the CoP using CtLC as a guide. The national team expanded on initial work on CtLC in Missouri to identify and revise activities such as in-person and online training based on principles of adult learning (Brock & Carter, 2017; Gotto et al, 2019), in-person group meetings, family information sessions, and virtual nationwide domain specific groupings to address the varied field of supporting families. The team built an expanded website and selected a user-friendly platform for conference calls and training activities. In-person and internet-based trainings used principles of adult learning. The national CoP assigned facilitators from UMKC and NASSDDS for each state and used the CtLC terminology and principles to clarify group communication. Most state CoPs supported families seeking support, information, and resources, but in some cases, families moved into advocacy roles to support other families.

The Launch phase encompassed recruiting, defining roles of members, and establishing communication channels. The Grow and Sustain phases were related to evaluation of successes, resources, and projects of members and determining if the CoP was sustainable, provided new opportunities, and if knowledge and outcomes within member groups were firmly established (Cambridge et al., 2005). Within the National CoP structure in this project, 16 participating states engaged in state-wide CoPs for supporting families using CtLC.

Charting the LifeCourse Framework. According to Cambridge et al (2005) CoPs connect a range of people, enable dialog and collaboration around a shared context, and generate knowledge. The content, processes, and tools of Charting the LifeCourse (CtLC) (Reynolds et al., 2012) provided a framework within the CoPs to promote systems change and improve

practices for supporting families within each state's unique context and across participating

states. Within the CoP, CtLC effectively focused the teams on the shared interest of supporting

families of people with disabilities (Domain of CoP model). The CtLC content and processes

addressed both systems change in policy/services to support families and engagement through

the targeted language of CtLC principles and practices (Practice of CoP). While addressing the

phases of CoP modeling, the national team used the consistent format of CtLC language,

processes, and supports to engage CoP members, extend knowledge, and inspire collaboration.

CtLC principles 1) are grounded in the core belief that ALL people have the right to live,

love, work, play, and pursue their life aspirations, regardless of disability status; 2) consider

people with disabilities in the context of family and community; 3) support families'

informational, social-emotional, and day-to-day needs; 4) support people with disabilities and

their families across life domains (community living, spirituality, health, safety, and advocacy)

and stages; 5) consider life stages and trajectories toward a good life within the family and

community; and 6) consider integrated services and supports throughout life (Reynolds et al.,

2012). CtLC's Integrated Supports Star addresses the reality of using both natural supports, often

unpaid or informal (Duggan & Linehan, 2013), and formal (paid) supports, if available. Not only

does the CtLC framework support people with disabilities and their families across time from

birth through aging, the CtLC trajectory tool to examine strengths, needs, and goals is also

applicable for group planning for systems change at multiple levels of policy and practice.

Throughout this project the principles and structure of the CtLC framework remained

consistent, but through the CoP process UMKC engaged in iteratively improving and

redesigning CtLC tools for supporting families in the domains of community living, spirituality,

health, safety, and advocacy The national team emphasized the importance of continuity and

change throughout life to spark social change and increase capacity over time (Elder, 1998). The

UMKC members of the National CoP team infused the CtLC framework into the CoP model for

intervention at the individual and policy levels as well as created a "common language" to

support NASDSSS's broader expertise for state systems change.

Examining CoP Processes and Outcomes

In 2017, ACL authorized Lewin researchers to begin a multiyear process and outcome

study of the ongoing National CoP using CtLC. A process evaluation is usually ongoing and

takes place during operation of a program, in this case focusing on the CoP structure, to find how

well the program is operating, if it is being implemented as designed, and if it is accessible and

acceptable to the focus population (Centers for Disease Control and Prevention, n.d.).

Researchers also studied outcomes within policy and practice of the overarching national CoP

and individual state CoPs using qualitative methods guided by the Value Creation framework of

Wenger et al. (2011). A useful framework to assess value creation "links specific activities to

desired outcomes" (Wenger et al., 2011, p. 7). This conceptual framework of value creation has

relevant indicators that both guide data collection and integrate indicators to better understand

outcomes of value creation, with the caveat that value creation is rarely linear in nature (Wenger

et al, 2011) except for the linkage between Realized and Reframed Values. However, the five

primarily non-linear Value Creation cycles of Immediate Value, Potential Value, Applied Value,

Realized Value, and Reframed Value do parallel the more linear phases of CoP creation and

sustainability described previously. Our research questions investigate the use of a CoP model

infused with the CtLC framework and tools to focus on supporting families within the

perspective of both a Process and Outcome evaluation: 1) How did the CoP structure and process

combine with the CtLC framework to impact participating state CoP activities?; 2) What themes

described overall intervention and policy outcomes for Value Cycles of the CoP process?; and 3)
what collective successes, challenges, and contextual elements influenced outcomes of the
national and state CoPs in supporting families?

Method

Participating States and CoP Members

This study involved the National CoP and 16 state CoPs listed in Table 1 that participated
for at least two years between 2013-2018. In 2013, the national team selected six states with
interest in policy change and at least one established practice for supporting families (Group 1)
in a nation-wide application process. Groups 2 and 3 joined the CoP in 2016, with Group 2 states
having prior exposure to CtLC. Group 3 states with little or no exposure to the CoP or CtLC
joined the CoP to engage in systems change and innovations to support families. Each of these
16 states provided data during two years of data collection (2018-2020).

Membership in each state's CoP was recruited by each developmental disabilities (DD)
agency and/or DD Council. Each state CoP had a blend of motivated people including state
officials interested in improving the lives of families, practitioners, people with a focus on
supporting family policy and practices, self-advocates, and family members. The national
leadership team of NASDDDS and UMKC provided a consistent means of training and
communication linkage through both in-person events and technology/social media connections.
States had a consistent national team facilitator as a point of contact to guide communication and
monitor monthly technical assistance calls. A core group of members in each state CoP engaged
in meetings, conference calls, and interactions at an intra-state and national level (e.g., CoP
meetings and CtLC National Showcase events) to share successes and discuss challenges.

Procedures

The Lewin researchers contacted UMKC and NASDDDS in 2017 to discuss the CoP model using CtLC principles and practices to begin the evaluation process. The data were publicly available in reports of project findings (Lewin, 2020, 2019), did not contain individual names within states, and were exempt from institutional review board review. During 2017, Lewin created measurement procedures in collaboration with the national team. First, researchers compiled descriptive data about state CoPs from designated leaders. (See Table 1). Then, online surveys described subsequently were used in 2018 and again in 2019 with additional follow-up phone interviews all based on indicators of each cycle of Value Creation (see Wenger et al., 2011 for specific indicators). In late 2018 and 2019, the team engaged in selected site visits. However, in the spring of 2020 site visits were replaced by Key Informant Interviews conducted on electronic platforms to respond to the COVID-19 pandemic. The national team served an advisory role during this study and met with Lewin upon request to share information, review founding documents, and identify primary contacts within each state. Lewin communicated with states via e-mail, participated in ongoing Technical Assistance calls hosted by the national project team, made site visits to seven states, and presented initial process information at the day-long in-person Annual CoP Meeting in Kansas City, Missouri in April 2019 and virtual meetings in late spring 2020.

Instrumentation

Online Surveys. Lewin used secure online response capture of closed- and open-ended survey questions to document overall progress and aspects of sustainability within Value Cycles one and two. Descriptive questions that had closed-end responses included "How are …1) individuals with IDD, 2) family members, 3) practitioners,4) others …engaged in CoP state leadership?" with possible responses of member/facilitator/trainer/advisor for policy/services

development/ other, please specify". Open-ended questions included: "How, and to what extent, did the National and state CoPs achieve consensus on a framework for supporting families", and "How, and to what extent, have the enhanced state policies, practices, and systems improved supports available to families?". See Lewin (2019) for a full listing of online survey questions. The Lewin team compiled and reviewed responses by states to document progress, identify gaps in responding to specific issues, and noted answers that needed additional clarification for the state CoPs and the National CoP function and outcomes.

Telephone Interviews. Based on Online Survey responses, the Lewin team created telephone interview guides including a core set of questions for each of the three groups of states in Table 1 which informed Value Cycles 3, 4, and 5. The interview questions addressed: 1) changes, successes, or challenges within state CoPs since completing the online survey; 2) more about accomplishments and improvements mentioned in reports; and 3) plans for state sustainability capacity and ability. For example, one question asked participants to describe the program or service change that influenced or resulted in the selected improvement(s) or change(s) you indicated in your state this year. Other items asked 1) how a state may have changed the way success was measured and 2) whether a state changed goals or strategies, both due to CoP participation. Each interview was recorded, transcribed, and informed subsequent site visits and Key Stakeholder Interviews.

Site Visits. After survey data were compiled, Lewin developed a site visit guide to sample outreach, communication, and findings for a representative sample of seven states (conducted as in-person visits in Indiana, District of Columbia, Missouri, Maryland, and Ohio and done virtually in Kansas and South Dakota). Site visit topics to inform Value Cycles 3, and 4

included environmental or contextual factors contributing to achievements, challenges or barriers

in states, and self-advocate and family access to supports and the CoP.

Key Stakeholder Interviews. In lieu of additional site visits due to COVID-19, Lewin

used online communication to interview other key stakeholders to inform Value Cycles 3, 4, and

5, such as family members and self-advocates, service providers, state employees, and program

head of agencies working to support families. This provided a broader response than the surveys,

interviews, and even the site visits since online communication methods expanded the pool of

informants. Funding for long-term services and supports and front door/ service entry supports

were investigated with Pennsylvania and South Dakota. Ohio responded on the role of families

in policy and service planning. Lewin asked Kansas about service planning and care

management processes in the state. Oklahoma and Washington responded about family access

and experiences of services and supports. Missouri elaborated on changes made in outcome

measurement for supporting families. Aspects of culture change in supporting families were

shared by Connecticut, the District of Columbia, Indiana, and Missouri. Again, interviews were

recorded, transcribed, and coded.   With each direct contact by telephone, site visit, or online

interview, the research team employed systematic field notes to record contexts and procedures.

Analysis

The research team used qualitative methods to review CoP processes and outcomes. A

social constructivist perspective (Charmarz, 2006), a subcategory of Grounded Theory

investigation (Creswell, 2007), guided the team to create meaning from diverse sources of

information, including written reports, telephone interviews, and in-person events compiled in

ATLAS.ti. First, researchers used open coding (Creswell, 2007) to code by value cycle to

iteratively create units of information or categories by states (Strauss & Corbin, 1990) organized

by specific indicators suggested for each Value Cycle (Wenger et al., 2011) to represent Process results. States had to report at least one instance of an activity in sufficient detail to be listed in able 2.

Next, an extended analysis of each Value Cycle's activities using axial coding (Creswell, 2007) accomplished the Outcome portion of this study to further examine how categories listed in Table 2 generated broader thematic outcomes. Researchers reinvestigated the data for context, strategies, and finally the outcomes of strategies (Strauss & Corbin,1990) to generate broader themes, again within the five stages of the Value Cycle evaluation model (Wenger et al., 2011). Again, two researchers identified summary themes and compared findings, settling disagreement by consensus. Throughout the data collection and analysis process, the team identified both challenges and successes using both the ATLAS.ti keyword index analysis of transcribed telephone interviews and site visits guided by researcher field notes.

Within qualitative research, researchers must validate the accuracy of findings by using strategies to examine the analysis process and findings (Creswell, 2007). First, the dependability of information in this study was confirmed by an audit by participating states and stakeholders. The use of multiple data sources in this process also enhanced data credibility (Patton, 1990). Next, researchers involved in the analysis were immersed in data collection of the survey, interview, and site visit processes, to confirm their familiarity with the multiple sources of data over time. Following confirmation of responses by state team participants, two authors who collected data through surveys, interviews, and direct contact, explored the data sources within each state and recorded these using ATLAS.ti before moving on to subsequent states. To ascertain reliability of codes, a third person familiar with the project and the ACL's supporting

families initiative reviewed the categorized data and any disagreements were settled by consensus.

Results

CoP Structure, Process, and Outcomes Across State Groupings

The three groups of 16 states in the study were stratified by entry date and/or previous experiences with CtLC (Table 1). Table 2 contains an overview of activities coded into categories within each state related to the Process of using the CoP model infused with CtLC content (Miles et al., 2014). Given the nature of the CoP objectives to collectively strengthen a state's networks, policies, and practices to support families, few unique activities within value cycles were associated with dates of entry into the CoP. An examination of the wide range of activities compiled in Table 2 showed that the three groups of states provided consistent and similar responses overall. Of note is that the activity in the Potential Value cycle, *reaching out to families*, was only mentioned by seven of the 16 states and *changes to recruiting/hiring processes* (Cycle 3, Applied Value) was less prominent across states. Results also showed that 9 of 16 states reported an *increased use of technology supports* within Cycle 4, Realized Value. Regardless of entry date, the National CoP team applied consistent training and principles of the CoP and CtLC to individualize strengths and needs of each state's CoP.

Themes of Outcomes Within Value Cycles

Cycle 1 - Immediate Value. Activities of immediate value to state CoP activities listed in Table 2 displayed the breadth of changes within the Process (implementation) evaluation to impact policy and practice for supporting families. We found that each group of states used the National CoP initiative to build partnerships within the state, enhance infrastructure, expand communication loops, and involve more people and groups that impact supporting families in

their states. The following themes represent more comprehensive, explanatory outcomes within this Immediate Value Cycle describing initial actions that may or may not eventually contribute to the overall Outcome (or effectiveness) Evaluation results of the project:

- **Collaboration between organizations was integral,** as state CoPs reached out to engage with organization in different systems (i.e. aging, UCEDDs, vocational rehabilitation) to create a shared vision for supporting families,

- **States listened to families and self-advocates,** and considered their perspectives.

- **Stakeholders within and beyond CoPs shared information and support**,

- **States derived benefit by establishing varied CoP organizational structure and processes.** Maryland had nine local CoPs that met regularly to exchange information on peer-to-peer supports, stakeholder engagement, and CtLC strategy application. Pennsylvania had 20 regional collaboratives to address regional perspectives on information and guidance.

- **Engagement with and buy-in from state agency leadership impacted the success of the CoP** (Lewin, 2020).

Cycle 2 - Potential Value. Looking across activities in Table 2, states reported changes in thinking and knowledge among people with IDD and their families, trainings, and sessions to share knowledge such as informal education or discussions. Here the National CoP supported leveraging diverse strategies in building knowledge and a focus on the CtLC language and values. State CoPs facilitated national team trainings often using the Ambassador Series, an online training developed and managed by UMKC. The national team offered collaborative learning sessions across state CoPs at the annual CoP meeting and CtLC Showcase in Kansas City. Themes included developing products and resources for dissemination; establishing new

initiatives for supporting families; and supporting community participation, advocacy, and competitive employment in more targeted ways. The following themes represent more comprehensive, explanatory outcomes within the Potential Value Cycle representing Outcome Evaluation results of the CtLC-infused CoP model:

- **Members' use of the CtLC tools and principles advanced consensus, within processes, trainings, and services,**

- **States deployed diverse strategies to build knowledge,** through training conducted at the national level to impact state-wide needs such as information, technology, and person-centered planning. For example, State CoPs used CtLC language and vision to reach out to families by increasing activities on cultural and linguistic competency (translation of materials, interpreters, etc.). The South Dakota CoP started a targeted outreach to native populations, Connecticut translated materials to Spanish, and the District of Columbia examined and edited materials to meet the needs of all families in their area of influence,

- **States targeted new and existing initiatives for change,** by embedding CtLC principles and practices into employment, education, transition support, and capacity building,

- **States leveraged technology to share information and resources**, using National CoP examples of Facebook, Zoom, and adjusting organization-based websites, and

- **Knowledge building led to new ways of thinking**, by changing the mind-set of families, professionals, and others navigating systems of support (Lewin, 2020).

    Cycle 3 - Applied Value. The national team supported states to engage in systems change in policy and practice using the CtLC framework within program and service operations. The numerous activities under Applied Value in Table 2 suggest how the leadership and

stakeholders in the state CoPs worked effectively to create outcomes to change policy and

practice. More comprehensive, explanatory outcomes of Applied Value further included:

- **States made changes to policies, programs, and services,** to advance supports to

   families (i.e. adopted legislation such as Employment First, more person-centered

   planning initiatives. DC adopted alternative to guardianship for family use),

- **States revised forms and processes to align with the CtLC framework,** making these

   more transparent and family-friendly,

- **States embedded the CtLC principles and tools into service operations and training**

   programs, in all state CoPs, using CtLC tools for strategic reframing or

   interventions/decision making,

- **States incorporated new measuring and monitoring processes,** (e.g., DC revised its

   Department on Disability Services complaint process), and

- **States created new staffing positions,** to increase capacity to support families (Lewin,

   2020).

   Cycle 4 - Realized Value. Within Cycle 4, the National CoP facilitated behavior changes

that improved performance in planning abilities and for advocating and accessing services. State

CoPs reported Realized Values listed in Table 2 such as: 1) use of the supporting families

definition in all materials, having a clearly defined framework using CtLC, and having agendas

for supporting families; 2) improved services and supports to families through increased

information, education, and training emphasizing best practice, connecting and networking with

other families, and services and supports of daily support and caregiving; 3) cultural changes in

leadership (e.g., greater advocacy, new approach to work); and 4) improved family satisfaction.

Realized Value outcome themes elaborate on Table 2 categories of activities to further inform

Outcome results:

- **People changed their behavior, by increasing involvement of families in leadership and planning processes and adding more holistic supports and services.** DC revised intake forms and improved services entry processes. In addition, a change occurred in the way structured planning meeting and problem-solving participants changed the way they interacted with families or in structured planning Connecticut, DC, Delaware, Hawaii, Kansas, Maryland, Oregon, and Pennsylvania CoP members described how the CtLC framework and tools provided a common language for planning across systems, elevated informal supports, and engaged diverse stakeholders,

- **State service systems increased access to and efficiency of services,** reporting an increase in the number of people served, improved communication on supporting families, and new ways to expand capacity for services and supports. The Washington CoP initiated the Individual and Family Services Waiver to operate more efficiently and increase services from 20 to 6,500 people new to DD services,

- **Staff, families, and self-advocates gained new skills,** for providing or navigating services and supports such as ways to navigate and access complex service systems, and

- **States increased the ability to overcome obstacles or crises** (Lewin, 2020).

    Cycle 5 - Reframing Values. Activities within Reframing Values listed in Table 2 show that states shared changes in goals, strategies, and systems operations that were the result of CoP participation and national team support. Reframing Value results are closely linked to the previous value cycle and represented effective systems change within CoP involvement. In terms

of Outcome Evaluation, Reframing Values themes listed below illustrate meaningful, comprehensive change within states' endeavors in supporting families:

- **States measured outcomes in new ways,** at all levels of services and supports. Indiana developed a quality monitoring system using CtLC.

- **State CoPs changed goals, strategies, and operations,** via CtLC support for work scopes, strategic plans, and evaluation methods to advance support to families. The Oklahoma CoP's systems-change strategy moved their focus from a formal service life to a "good life", a tenet of CtLC. Maryland moved top-down decision making to include more stakeholders and groups within the state to effect systems change, and

- **States aligned their systems' values to form a common vision for supporting people with IDD and their families,** (i.e., focus on community integration and making sure families can access information and services across the life course), (Lewin, 2020).

The identified changes in knowledge capital and practice lead to redefining how CoPs were measuring outcomes and changing goals, strategies, or system operations because of CoP involvement. Outcomes of Reframing Value represented a significant change in how state DD agencies approached families and business practices by considering community resources first and considering the individual with disabilities <u>and</u> families in policies and practices.

Reported Consensus and Sustaining Change within the National CoP with CtLC

State CoPs reported value in the National CoP to promote state and national consensus on the national team agenda to improve policy and practice to support families of persons with disabilities. "Key activities that build consensus include gaining buy-in from state agency leadership, focusing on grassroots efforts, engaging with stakeholders, and building staff capacity" (Lewin, 2020, p. 25). State CoPs noted that the CoP helped to build consensus through

a common language and values within and across states. Stakeholders (professionals, families, self-advocates) used CtLC principles and tools to further the supporting families agenda.

Consensus building in some states on systems change was impacted by leadership changes in state agencies, budget restrictions, and lack of staff commitment related to the voluntary nature of CoP involvement at local and state levels. Differing abilities of staff and the slow nature of policy change at the government level represented challenges to altering systems.

The CoP enhanced state policies and practices within systems change.

"Key activities that helped states enhance their capabilities to provide support to families include incorporating CtLC principles into institutional practices, aligning state outcomes with the CtLC framework, aligning goals and values across different agencies, providing services across the lifespan, and using the CtLC framework to develop new state policies, practices, and system processes" (Lewin, 2020, p. 25).

As evidence of sustainability, the National CoP increased by five states in 2019. Since initial funding, the National CoP with CtLC employed fee-based subscriptions to continuously support evolving person- and family-centered practices across service systems such as early childhood intervention, schools, transition to adulthood, vocational rehabilitation, and aging. Combined with 16 state CoPs in this analysis, the national team continues to provide a viable, flexible, and ongoing structure for supporting families throughout the United States with sustainability linked to CtLC principles, training, and tools in multiple domains and ages.

"Sustainable change often requires states to adopt their policies, practices, and procedures to reflect statewide goals" (Lewin, 2020, p.27). Sustainability was built into state infrastructure and leadership to support families. To enhance capacity, states shared activities such as creating new staffing positions for the CoP, using CtLC in onboarding protocols for new staff, mentoring

local and regional CoPs within states, designating a small but dedicated CoP team, and training state leadership on the application of person-centered practices within supporting families initiatives. At a grassroots level, CoPs worked to increase capacity of families to self-support and increase linkages in communication, information, and use of CtLC tools and domains.

Discussion

Process and Outcome results show the value of using a CoP model to form the National CoP on Supporting Families. Although staggered entry into the CoP process yielded slight differences in some value cycles, analysis showed that some of the last states entering the CoP also advanced their agenda on supporting families. The CtLC framework was central to the context and content of the National CoP while being flexibly applied to individual state CoP activities as an intervention and mechanism for strategic reframing of state orientations to supporting families of people with IDD. CtLC principles may influence people to think more creatively or differently as to integrated supports in the community, as well as serve to inform policy and practice within broader systems of support at state and Federal levels. Also, the process of using the CtLC Trajectory for planning and evaluation proved to be useful. In most cases, using CtLC encouraged both families and leaders in public policy to focus attention on the problem at hand using the trajectory designed for both individual and state-focused goals.

The effective use of the CoP process and CtLC framework was affirmed by leadership of the national team and state CoPs. Yet another indicator of the value of the National CoP on Supporting Families is that states continued to engage in CoP use on a subscription basis. The longevity and sustainability of the CoP using CtLC framework within and among states illustrates the viability and effectiveness of this continuously evolving effort in supporting families with IDD.

However, beyond the success of the National CoP initiative, there is still a need for a

more targeted research agenda to promote supporting people with disabilities and their families

across cultures, communities, states, regions, and services. Although some outcomes for

supporting families show changes in a positive direction, there is a need for more accountability

from research teams and provider groups regarding evidence for efficacy, social validity, and

cost-benefit analysis at all levels of implementation of either research or practice (Hecht et al.,

2011). As technology and improved practices evolve, it is important to build bi-directional

communication with families in funded and community-based services.

Flexible methods within programs and services are needed to meet the complex needs of

families regarding culture, socioeconomics, and life course issues. For example, how can we

elevate the needs of families with people with IDD at all life stages? Is there an overlap of

services by age such as school-based educational services that stop in early adulthood, without

assurance for ongoing needs for supporting families? How can families feel supported by their

communities, regions, and states, as well as at federal levels? One solution may be to make a

concerted effort to build "whole family" advocacy capacity for all cultures across ages and

stages. It is critical to address supporting families within their own unique context, ensuring that

we recognize the diversity of families overall. Also, building leadership opportunities for

families at local, state, and national levels is important. A cohesive linking of research to practice

and policy can build family-driven agendas to impact quality of life for all people with IDD.

In addition, COVID-19 and the ensuing pandemic in 2020 has impacted people with

disabilities and their families in ways that are only beginning to be measured at the time of this

writing. For example, a disruption in services which intensified the isolation of people with

disabilities and the health of family caregivers and direct support professionals changed typical

practice. Thompson and Nygren (2020) wrote "The coronavirus (COVID-19) pandemic has affected, and will continue to affect, every aspect of the IDD community" (p.257). This includes the need to continuously support families as primary caregivers in the changing society so that funding and policy initiatives meet the needs of people with IDD and their families, even in the face of a global lack of resources (Thompson & Nygren, 2020).

Limitations

The following limitations of this study are noted here. First, results focused on retrospective data of self-reported activities and actions of state CoPs, which may have affected responses. State teams were asked to complete surveys and give information on activities that occurred in the past. Another limitation is that data were collected after the initial grant ended, when states voluntarily participated in a fee-based CoP. Also, the staggered entry of groups of states into the CoP process may have limited the impact of the CoPs within and across states.

Although the leadership process and leader attributes or styles were not evaluated as part of this CoP model, it is possible the differential selection and functional leadership of state CoPs could influence CoP outcomes. The scope of this study influenced whether site visits were conducted face-to-face or virtually, limiting consistent data collection methods. In addition, the researchers modified their data collection format during the COVID-19pandemic in spring 2020.

Conclusion

The CoP model infused with CtLC framework in state CoPs linked the flexible but targeted strategies, established principles, and resulting practices of CtLC to build capacity and policy supports for families with people with IDD. Value Creation cycle evaluation reflected the progress made by states within the National CoP for systems change in policy and practice in

supporting families. The National CoP continues to evolve beyond this study illustrating the

ongoing commitment of state leadership teams for supporting families using CtLC.

References

AAIDD (2019). Position statement on supporting families. https://www.aaidd.org/news-

      policy/policy/position-statements/family-support

Brock, M. E., & Carter, E. W. (2017). A meta-analysis of educator training to improve

      implementation of interventions for students with disabilities. *Remedial and Special Bid*

      Education, 38(3), 131–144. https://doi.org/10.1177/0741932516653477

Brown, I, Radford, J. P. & Wehmeyer, M. L. (2017). Historical overview of intellectual and

      developmental disabilities. In M. L. Wehmeyer, I. Brown, M. Percy, K. A. Shogren, &

      Fung, W. L. A. (Eds.) *A comprehensive guide to intellectual & developmental disabilities*

      (2nd ed., pp. 19-34). Brookes Publishing.

Buntinx, W. H. E. (2013). Understanding disability: A strengths-based approach. In M. L.

      Wehmeyer (Ed.), *The Oxford handbook of positive psychology and disability*

      (pp. 7-18). Oxford University Press.

Cambridge, D., Kaplan, S. & Suter, V. (2005). *Community of practice design guide.*

      https://library.educause.edu/resources/2005/1/community-of-practice-design-guide-a-

      stepbystep-guide-for-designing-cultivating-communities-of-practice-in-higher-education

CMS (2014). Fact Sheet: Home and Community-Based Services.

      https://www.medicaid.gov/sites/default/files/2019-12/final-rule-fact-sheet.pdf

Charmaz, K. (2006). *Constructing grounded theory*. Sage.

Creswell, J. W. (2007). *Qualitative inquiry & research design.* Sage.

Duggan, C., & Linehan, C. (2013). The role of 'natural supports' in promoting independent

      living for people with disabilities: a review of existing literature. *British Journal of*

      Learning Disabilities, 414, 199-207.

Elder, G. H. (1998). The life course as developmental theory. *Child Development, 69(1)*, 1-12.

>   http://www.jstor.org/stable/1132065

Grossman, B. R. & Magaña, S. (2016). Introduction to the special issue: Family support of

>   persons with disabilities across the life course. *Journal of Family Social Work, 19*(4),

>   237-251. http://dx.doi.org/10.1080/10522158.2016.1234272

Gotto, G. W., Reynolds, M., Palmer, S. B., & Chiang, D. (2019). Supporting families through the

>   charting the LifeCourse framework. *Intellectual and Developmental Disabilities, 57(1),*

>   56-65. https://doi.org/10.1352/1934-9556-57.1.56

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. Johnson

>   Foundation.

>   http://supportstofamilies.org/wp-content/uploads/WingspreadReport-2012-Rev-52912-
>   Compressed.pdf

Larson, S. A., Eschenbacher, H. J., Taylor, B., Pettingell, S., Sowers, M. & Bourne, M. L.

>   (2020). *In-home and residential long-term supports and services for persons with*

>   *intellectual or developmental disabilities: Status and trends through 2017.*

>   University of Minnesota, Research and Training Center on Community Living, Institute

>   on Community Integration. http://nasuad.org/sites/nasuad/files/2015_RISP-WEB.pdf

Lewin (2020). *National Community of Practice for Supporting Families Evaluation*

>   *Final Report 2018-2020.* Administration for Community Living.

Lewin (2019). *National Community of Practice for Supporting Families Evaluation*

Annual Report 2018-2019. Administration for Community Living.

    https://acl.gov/sites/default/files/programs/201910/ACL_CoP_Annual_Report_Final_SF_

        508.pdf

Martin, L., Grandia, P., Ouellette-Kuntz, H., & Cobigo, V. (2016). From framework to practice:

    Person-directed planning in the real world. *Journal of Applied Research in Intellectual*

    Disabilities, 29, 552-565. Http://doi:10.1111/jar.12214

Miles, M. B., Huberman, A. M., & Saldana, J. (2014). *Qualitative data analysis: A methods*

        sourcebook (3rd ed.). Sage.

Patton, M. Q. (1990). *Qualitative evaluation and research methods.* Sage.

Reynolds, M. C., Gotto, G. S., Agosta, J., Arnold, K., & Fay, M L. (2016). Supporting families

        across the life course. In *Critical Issues in Intellectual and Developmental Disabilities:*

        Contemporary Research, Practice, and Policy (pp. 175-187). AAIDD.

Reynolds, M. C., Palmer, S. B., & Gotto, G. S. (2018). Reconceptualizing natural supports for

    people with disabilities and their families. *International Review of Research in*

    *Developmental Disabilities, 54,*177-209. https://doi.org/10.1016/bs.irrdd.2018.07.006

Reynolds, M. C., St John, J., & Gotto, G. S. (2012). Scaling up self-determination

    Through family support. In S. B. Palmer, T. Heller, G. S. Gotto, J. Peterson-Besse, & M.

    C. Reynolds Eds.), *Research to practice in self-determination: Family focus on self-*

    determination (pp. 24-26). http://ngsd.org/sites/default/files/research_to_practice_sd_-

        _issue_4.pdf

Strauss, A. & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and*

        techniques. Sage.

Thompson, J. R. & Nygren, M. A. (2020). COVID-19 and the field of intellectual and

developmental disabilities: Where have we been? Where are we? Where do we go?.

   Intellectual and Developmental Disabilities, 58(4), 257-261.

Thompson, J. R. & Viriyangkura, Y. (2013). Supports and Support needs. In M. L. Wehmeyer

   (Ed.) *The Oxford handbook of positive psychology and disability* (pp. 317-337). Oxford

   University Press.

Turnbull, H. R., & Turnbull, A. P. (2000). Family support: Retrospective and prospective. In

   M. L. Wehmeyer, & J. R. Patton (Eds.), *Mental retardation in the 21st century* (pp. 3-17).

   ProEd.

Wehmeyer, M. L. (2013). Beyond pathology: Positive psychology and disability. In

   M. L. Wehmeyer (Ed.), *The Oxford handbook of positive psychology and disability (pp.3-*

   6). Oxford University Press.

Weeks, L., Nilsson, T., Bryanton, O., & Kozma, A. (2009). Current and future concerns of older

   parents of sons and daughters with intellectual disabilities., Journal of Policy and Practice

   in Intellectual Disabilities, 6, 180–188. https://doi.org/10.1111/j.1741-1130.2009.00222.x

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. https://wenger-

      trayner.com/resources/publications/evaluation-framework/

Wenger-Trayner, E., & Wenger-Trayner, B. (2015). *Communities of Practice: A Brief*

   Introduction. http://wenger-trayner.com/wp-content/uploads/2015/04/07-Brief-

   introduction-to-communities-of-practice.pdf

Table 1

State CoPs, Organizing Teams, and Key Informant Interview Participants by Group 2012-2018

Group	States	Organization of State CoPs	Key Informant Interview Participating Organizations*
2012-2013 Grant funded; continued to participate as Fee-based units	Connecticut	Formal CoP structures, highly structured leadership teams, held regular meetings	Depart. of Developmental Disabilities (DD), Capital Region Educational Council, DD Council
	District of Columbia		DD Council, Dept. on Disabilities Services
	Missouri (2012 mentor state in initial pilot study of CoP/CtLC and ongoing CoP)		Abilities First, Division of DD, Missouri Family-to-Family, Family Advocacy and Community Training, ARC of St. Louis, Learning Opportunities/Quality Works, County Connections, Progressive Community Services
	Oklahoma		The University Center for Excellence in DD (UCEDD), DD Services Division
	Tennessee		NA
	Washington		Informing Families, ARC of Snohomish County
Pre-2016 Expansion States with exposure to CtLC joined CoP as Fee-based units	Maryland	Less-structured state CoPs, but active participants in National CoP	NA
	Ohio		Miami County Board of DD, Northern Ohio Family-to-Family
	Pennsylvania		Office of Developmental Programs
	South Dakota		Division of DD, Research for Human Development
2016 Fee-based CtLC -new to CtLC/CoP	Alabama	Individually structured state CoPs unique to each state, but fully participated in National CoP events and meetings	NA
	Delaware		NA
	Hawaii		NA
	Indiana		Division of Disability and Rehabilitative Services, Bureau of DD, Indiana Professional Management Group, Self-Advocates
	Kansas		DD Council, Sunflower Health Plan (Managed care), Systems of Care (Managed care),

	Oregon		NA	

*Each state participated in all surveys and telephone interviews, with Key Informant Interviews to further investigate topics of interest held in 10 of the 19 states.

Table 2

Variety of State Value Cycle Activities and Open-Coded Categories During or Before Entry to the CoP, and Not Applicable (N/A)

Cycle 1 – Immediate Value Activities* of State CoP Participation Facilitating Policy and Practice Changes in Later Cycles

	During CoP				Before CoP				N/A**			
	Total States $N=16$	Grp 1 $n=6$	Grp 2 $n=4$	Grp 3 $n=6$	**Total States** $N=16$	Grp 1 $n=6$	Grp 2 $n=4$	Grp 3 $n=6$	**Total States** $N=16$	Grp 1 $n=6$	Grp 2 $n=4$	Grp 3 $n=6$
Sharing information	**16**				0				0			
Providing peer-to-peer support	**10**	5	2	3	**0**				6	1	2	3
Promoting collaboration between organizations	**16**				**0**				0			
Listening to family/self-advocate perspectives	**12**	6	3	3	**3**		1	2	**1**			1
Connecting to national CoP	**12**	4			**1**	1			**3**	1	1	1
Establishing state CoP structure	**15**	5	4	6	**1**	1			**0**			
Engaging state agency leadership	**13**	6	4	3	**1**			1	**2**			2
Engaging CoP members	**7**	4	1	2	**5**	2	2	1	**4**		1	3

Cycle 2 – Potential Value Activities* - Changes in Knowledge Capital to Produce Future Outcomes

	During CoP				Before CoP				N/A**			
	Total States $N=16$	Grp 1 $n=6$	Grp 2 $n=4$	Grp 3 $n=6$	**Total States** $N=16$	Grp 1 $n=6$	Grp 2 $n=4$	Grp 3 $n=6$	**Total States** $N=16$	Grp 1 $n=6$	Grp 2 $n=4$	Grp 3 $n=6$
Using CtLC tools/principles	**14**	5	3	6	**2**	1	1		**0**			
Conducting national training	**13**	5	3	5	**2**		1	1	**1**	1		
Conducting state training	**15**	5	4	6	**1**	1			**0**			
Conducting informal training/education	**15**	6	4	5	**1**	1			**1**			1
Reaching out to families	**7**	2	1	4	**5**	1	3	1	**4**	3		1
Creating/disseminating products	**12**	6	4	2	**0**				**4**			4
Diffusing CtLC across sectors	**12**	4	3	5	**2**	1	1		**2**	1		1
Identifying innovation/focus areas	**14**	5	4	5	**0**				**2**	1		1

	Total States N=16	Grp 1 n=6	Grp 2 n=4	Grp 3 n=6	Total States N=16	Grp 1 n=6	Grp 2 n=4	Grp 3 n=6	Total States N=16	Grp 1 n=6	Grp 2 n=4	Grp 3 n=6
Advancing current initiatives/goals	**13**	6	3	4	**0**				**3**		1	2
Participating in workgroups/learning communities	**8**	4	2	2	**0**				**8**	2	2	4
Creating websites/technologies	**11**	5	3	3	**0**				**5**	1	1	3
Changes in thinking/knowledge	**16**				**0**				**0**			
Increased number of CtLC Ambassadors/Champions	**8**	2	2	4	**0**				**8**	4	2	2
Increased awareness/knowledge of CoP goals	**5**	1	2	2	**0**				**11**	5	2	4

Cycle 3 – Applied Value Activities* – Reported Changes in Policy and Practice Linked to Innovative Knowledge

	During CoP				Before CoP				N/A**			
	Total States *N=16*	Grp 1 *n =6*	Grp 2 *n=4*	Grp 3 *n=6*	**Total States** *N=16*	Grp 1 *n=6*	Grp 2 *n=4*	Grp 3 *n=6*	**Total States** *N=16*	Grp 1 *n =6*	Grp 2 *n=4*	Grp 3 *n=6*
Changes to policy	**15**	6	4	5	**0**				**1**			1
Changes to program/services	**11**	2	4	5	**0**				**5**	4		1
Revisions to ISP or other forms/processes	**12**	4	3	5	**0**				**4**	2	1	1
Embedding CtLC principles/tools into operations	**15**	6	4	5	**1**		1		**0**			
Starting new initiatives	**10**	4	3	3	**0**				**6**	2	1	3
Aligning with other initiatives	**11**	6	2	3	**0**				**5**		2	3
Changes to recruitment/hiring practices	**3**	1	1	1	**0**				**13**	5	3	5
Creating new staffing positions	**9**	4	4	1	**1**		1		**6**	2		4
Improved skills/capabilities of staff	**10**	4	3	4	**0**				**6**	3	1	2
Measuring/monitoring services	**14**	6	3	5	**0**				**2**		1	1
Increased use of technology supports	**9**	5	2	2	**0**				**7**	1	2	4

Cycle 4 – Realized Value Activities* – Reported Performance Improvement in Supporting Families via New Practices

	During CoP				Before CoP				N/A**			
	Total States N=16	Grp 1 n=6	Grp 2 n=4	Grp 3 n=6	Total States N=16	Grp 1 n=6	Grp 2 n=4	Grp 3 n=6	Total States N=16	Grp 1 n=6	Grp 2 n=4	Grp 3 n=6
Less reliance on formal services	**4**	1	0	3	**0**				**12**	5	4	3
Reduction in waiting list/time spent at the front door	**7**	4	3	0	**0**				**9**	2	1	6
Changed behavior	**13**	5	4	4	**2**	1		1	**1**			1
Better experience with services/ systems navigation	**4**	1	0	3	**1**			1	**11**	5	4	2
Increased access/ efficiency	**13**	6	4	3	**0**				**3**			3
Increased satisfaction/ better lives	**7**	3	3	1	**2**	1		1	**7**	2	1	4
New skills for using and/or providing services (staff, families, self-advocates)	**13**	6	3	4	**0**				**3**		1	2
Increased ability to overcome obstacles/crisis	**8**	4	1	3	**0**				**8**	2	3	3
Change in use of services	**11**	4	3	4	**0**				**5**	2	1	2

Cycle 5 - Reframing or Redefining Success Activities* of Using CoP for Supporting Families- Sustainable Outcomes

	During CoP				Before CoP				N/A**			
	Total States N=16	Grp 1 n=6	Grp 2 n=4	Grp 3 n=6	**Total States** N=16	Grp 1 n=6	Grp 2 n=4	Grp 3 n=6	**Total States** N=16	Grp 1 n=6	Grp 2 n=4	Grp 3 n=6
Measuring outcomes in new ways as a result of the CoP	7	3	1	3	**0**				9	3	3	3
Changes in goals/strategies/system operations as a result of the CoP	16	6	4	6	**0**				0			
Aligning system values across the state – state agencies share same vision for supporting families	11	5	2	4	**0**				5	1	2	2

* An activity was noted if a state reported sufficient detail, i.e. name, purpose, inception date or implementation information.

**In some cases, an activity was not a focus of state CoP