SUPPORTING FAMILIES
of individuals with intellectual & developmental disabilities

THE NATIONAL COMMUNITY OF PRACTICE • FUNDED BY THE ADMINISTRATION ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES

National Community of Practice
for Supporting Families of Individuals with
Intellectual & Developmental Disabilities

Year Two Report
October 2014

This report chronicles Year Two of the National Community of Practice on Supporting Families initiative. This project is funded by the Administration on Intellectual and Developmental Disabilities (AIDD) and employs a learning community approach among participating states to create policies, practices and systems to better assist and support families that include a member with intellectual and developmental disabilities across the lifespan.

supportstofamilies.org

National Community of Practice on Supporting Families
Year Two Report
October 2014

Prepared for

Administration on Intellectual and Developmental Disabilities
One Massachusetts Avenue NW
Washington, DC 20001

Prepared by

Michelle Reynolds and Megan Birzer
Institute for Human Development
University of Kansas City – Missouri
215 W. Pershing Road, 6th Floor
Kansas City, MO 64108
www.ihd.umck.edu

Mary Lee Fay
National Association of State Directors of Developmental Disabilities Services
113 Oronoco Street
Alexandria, VA 22314
www.nasddds.org

John Agosta and Yoshi Kardell
Human Services Research Institute
7690 SW Mohawk Street
Tualatin, OR 97062
www.hsri.org

supportstofamilies.org

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Introduction

In 2012, the US Administration on Intellectual and Developmental Disabilities (AIDD) awarded funding to the National Association of State Directors of Developmental Disabilities Services (NASDDDS) to create a Community of Practice (CoP) focused on expanding the knowledge base around how to best support families with members with intellectual and developmental disabilities.

> **Our Goal**
>
> 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 across the lifespan.

Along with NASDDDS, the core project team includes the Institute for Human Development at the University of Missouri – Kansas City (UM-KC), and the Human Services Research Institute (HSRI). In addition to the core project management team, an advisory group of national partner organizations provide guidance to the project and includes the Association of University Centers on Disabilities (AUCD), Autistic Self Advocacy Network (ASAN), National Association of Councils on Developmental Disabilities (NACDD), Parent-to-Parent USA, Self-Advocates Becoming Empowered (SABE), and Sibling Leadership Network (SLN). A number of key consultants recognized nationally as experts in the area of supporting families also lend their expertise to the project. The following provides a description of Year Two activities, lessons learned, and next steps.

The investment in this five year project directly relates to one of the four key recommendations generated by a group of national leaders in the disability field at the Wingspread Family Support Summit in 2011[1], that specified to "*Develop and fund National Supporting the Family Initiatives that explore principles, practices, and data indicators that will inform practice and policy related to supporting families across the lifespan.*" In alignment with this recommendation, the goal of this initiative is 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 across the lifespan.

Over the course of this five year effort, the project team aims to achieve the following outcomes:

- State and national consensus on a national framework and agenda for improving support for families with members with I/DD.

- Enhanced national and 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.

The purpose of this report is to build on activities conducted during year one of the project and provide a description of the activities and achievements associated with the second year of the project. What follow is a description of: (a) the evolution of the systems change and the LifeCourse Framework, (b) Year Two activities of the national Community of Practice level as well as state level activities, (c) lessons learned, and (d) next steps.

Community of Practice Design and Purpose
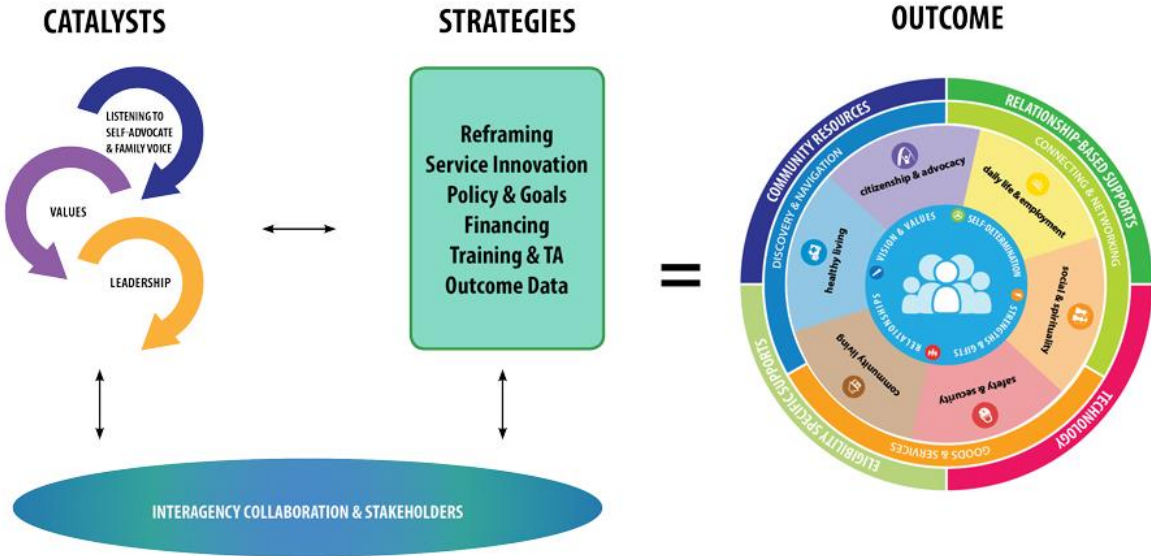
Framework for Systems Change

A systems change framework was developed for the Community of Practice and was modeled after previous work of the Support Employment Leadership Network (SELN). The SELN framework is evidence-based, and has been widely accepted as best practice. There are several components of the systems change framework and

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each component works with the others to drive systems change. The components include catalysts, leadership and principles, and a set of performance indicators.

Figure 1: Systems Change Framework, 2013

During Year Two of the project, the systems change framework evolved in response to a growing understanding of the systems drivers. The components were divided further to include catalysts, infrastructure, innovations, and outcomes. Each of these components grew to include multiple indicators. Indicators related to catalysts include input from self-advocates and families, values, and leadership. Indicators related to infrastructure include reframing, space for innovation, policy and goals, financing, training and technical assistance, and outcome data. Indicators of innovative strategies are related to the experience of individuals and families prior to accessing formal services, service delivery, Medicaid waivers, family networks/peer support, wait list, and person and family-centered planning. Another addition to the systems change framework was to include the LifeCourse guiding principles as an influence on all components.

The development of the concepts of the systems change framework over time is reflected in the graphic representations of the framework from year one to year two. The original framework is depicted in Figure 1, and Figure 2 represents the updated version in 2014.

Figure 2: Systems Change Framework, 2014
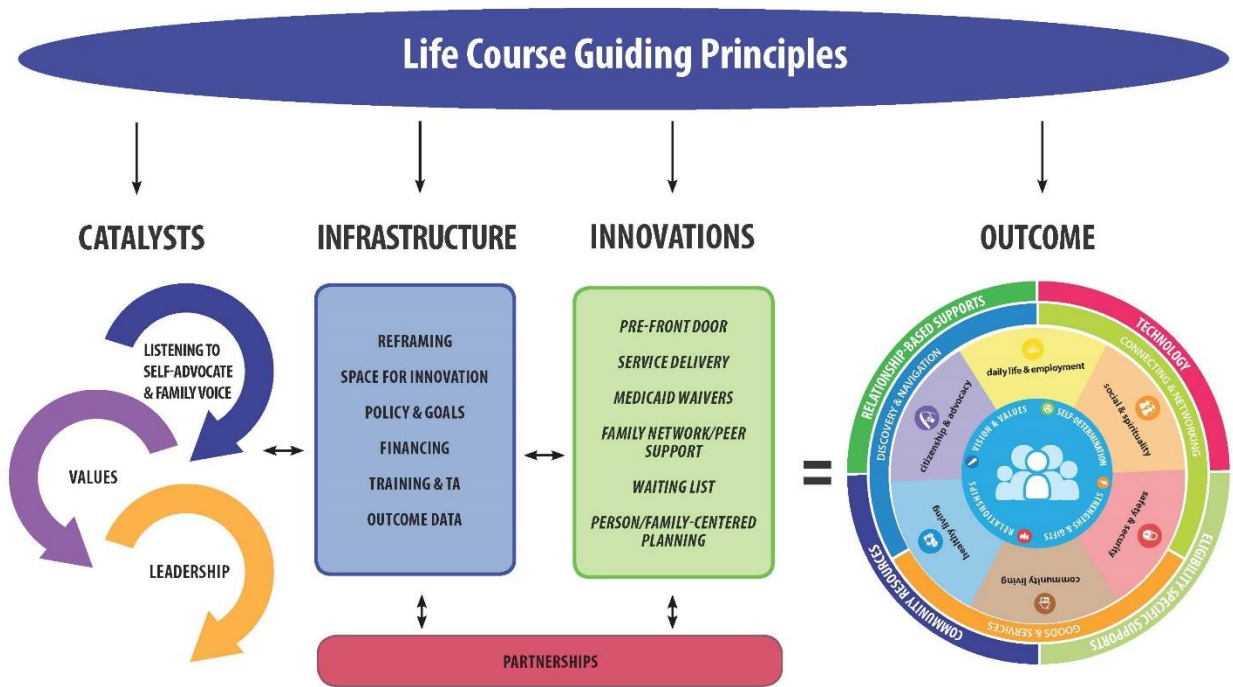
Adapted from Hall et all, 2007

Underpinning all the work in the Community of Practice is a commitment to the LifeCourse framework. LifeCourse theory has been defined as an "interdisciplinary theory that seeks to understand the multiple factors that shape people's lives from birth to death, placing individual and family development in cultural and historical contexts" (Hutchison, 2014). This LifeCourse Framework is the theoretical platform that states use to guide all their work on supporting families. The framework encompasses several key components depicted in Table 1.

Table 1: LifeCourse Framework Elements

Element	Description	Questions to Consider
All People with IDD	This includes those receiving formal state DD services, known to the state DD agency but not receiving services (wait list, TCM only), and not known to state DD service system.	Who is being considered and/or addressed in this strategy? During exploration and planning, was the 100% considered?
Family	The role of the family and impact on the family are considered including: • Family defined by the individual or legal/blood related parent • All family member relationships considered (parents, siblings, etc.) • Family cycle recognized • Reciprocal role of member with disability in the family recognized	Was the role of family or the impact on family considered or addressed in this strategy?

Element	Description	Questions to Consider
Support Needs	Includes one or all of these support areas: • **Discovery & Navigation**: Educational, Informational, and Skill Building • **Connecting & Networking**: Emotional Support/Self-Efficacy • **Goods & Services**: Activities of daily living/instrumental activities of daily living and/or financial	What needs are being addressed by this strategy?
Life Outcomes	This includes a focus on life experiences and assists the individual with the disability and/or their family to develop a vision or aspirations for a quality of life.	Is it based on current support structures that focus on self-determination, community living, social capital and economic sufficiency? Is there are a focus on "life experiences" and life outcomes or only on supports? Does this strategy assist the individual with the disability and/or their family to develop a vision or aspirations for a quality of life?
Life Domains	Includes one or all of these domains: Daily Living/Employment, Safety and Security, Community Living, Healthy Lifestyle, Social and Spiritual	Is there are recognition of the specific and integrated life domain that is being addressed?
Life Stages and Trajectory	Includes one or all of these stages: Prenatal/infancy; early childhood; school age; transition; adulthood; and aging. Considers the response to the current need as well as the impact on the future.	Is there a focus on a specific life stage, but awareness of prior or future life stages? Does this strategy consider the response to the current need **and** the impact on the future?
Integrated Delivery of Supports	Includes one or all of these types of support: • **Personal or Family Strengths and Assets**: Own skills (drive a car, stay at home by self), family (owns the home) • **Technology**: Technology as the "support" or technology to assist in the life domain • **Community Supports**: Supports are provided by something all community members can access, even if it requires payment • **Peer Support**: Supports provided by a family, friend or other relationship (coach, teacher, etc.) • **Eligibility Based Supports**: Disability or	Are one or more integrated supports being considered in this strategy?

Element	Description	Questions to Consider
	financial eligibility to receive public supports (Medicaid, HUD, VR, etc.)	
Policy and Systems	Policies and systems involve the people it impacts at all levels, are person/family driven and centered, sufficient to meet the needs, and fair.	What mechanisms are in place to measure systems efficiency and quality?

The ways in which IDD systems developed over time, have often led to services and supports that are, for the most part, reactive and crisis driven, addressing isolated life domains or discrete episodes of need. The LifeCourse Framework offers a more holistic approach to planning the life trajectories of both individuals and family units. This framework provides a way to understand supports to both persons with disabilities and their families across the lifespan. Additionally, the LifeCourse Framework is not specific to disability but rather applicable to the human experience. Through the work of the Community of Practice, the LifeCourse Framework continues to evolve, and be validated.

Year Two Activities

Year Two activities build on the foundation developed over the course of Year One. The following describes project activities undertaken during Year Two at the National Community of Practice level and state team level.

National Community of Practice Activities

The national project team is responsible for managing the activities of the Community of Practice including organizing and convening monthly calls with all the of the participating states, providing technical assistance, hosting additional webinar training opportunities to enhance learning across the states related to a particular topic, and convening an annual meeting. In addition to these regularly scheduled activities, members of the national project team engaged in a number of information dissemination and networking activities, which are described in more detail below.

Conference Presentations

The learning from the Community of Practice was shared at seven conferences in Year Two. The presentations focused on both the Community of Practice itself, and the LifeCourse Framework, and included Keynote sessions, Breakout sessions, and Poster sessions.

- NASDDDS – Keynote, November 14-15, 2013
- AUCD – Pre conference session, November 17-19, 2013
- TASH – Breakout session, December 12-13, 2013
- AMCHP – Poster session, January 27-28, 2014
- AAIDD – Post session, June 24-27, 2014
- Reinventing Quality, August 3-5, 2014
  - National CoP – Breakout session
  - LifeCourse Framework – Poster session
- HCBS – September, 2014

Virtual Information Dissemination

There were multiple ways the Community of Practice disseminated information virtually in Year Two including.

- **National Community of Practice for Supporting Families Website** www.supportstofamilies.org
  The National Community of Practice for Supporting Families of Individuals with I/DD website was established February of 2013. It started as a static one-page website to share basic information about the project and later to recruit states to participate in the project and submit their intent and proposals. In April of 2014, as the project expanded into its second year, the website was revamped with WordPress to create a more dynamic web presence around supporting families. Each state team has its own page to highlight state team updates and information. In addition, products and media from the project are all collected and hosted on this platform, which is accessible to the public.

  Since April 2014, 1,585 users have navigated a total of 2,380 sessions on the current supportstofamilies.org website. Direct traffic to the website (where people used the project's URL) accounted for 36.85% of all traffic, organic search accounted for 25.38%, social media accounted for 17.73% of traffic, another 17.23% of users were referred from other websites, and 2.82% came from emails.   Almost 65% of sessions navigated on the website from new users. The most common pages accessed included Tools & Downloads, LifeCourse Framework, Guiding Framework, Project Overview and the state team pages. Project staff uses Google analytics to evaluate website data and monitor usage and user behavior.

- **Social Media**

  The National Community of Practice for Supporting Families of Individuals with I/DD project currently has a presence on three social media channels: Facebook, Twitter, and Google+. Project staff use Hootsuite to facilitate and manage social media posts and interactions. Through integrations with the WordPress on the website, each time a new post announcing a new product, project update, or other news related supporting families is created at supportstofamilies.org, all project social media channels are automatically updated.

  Facebook

  The Community of Practice for Supporting Families with Disabilities Facebook page (http://facebook.com/supportstofamilies) was established in April 2013 and currently has 905 likes. The page is the result of 1) recommendations following the Wingspread meeting to establish mechanisms to maintain ongoing dialogue with families, service system representatives and other key stakeholders involved in supporting families, 2) an objective in the Community of Practice grant to establish a web presence and other mechanisms to collect, maintain, and disseminate information across states and 3) collaboration with KU's Beach Center, which is well known for their expertise and expansive research and work in effective supports for families. After Wingspread (March 2011), a virtual community of practice was established on Facebook in May 2011 to promote sharing knowledge and ideas about effective practices and innovative strategies for supporting families (called National Agenda for Family Support). As a result of collaboration around supporting families after Wingspread and the establishment of the CoP project, project staff at IHD discovered that the Beach Center had been hosting a virtual Community of Practice on Facebook and reached out to them about merging the two virtual communities. As a result, the two pages were merged in April of 2013.

- **Twitter**

  Currently, @familieswidd (http://twitter.com/familieswithidd) has 434 followers. The National CoP's Twitter profile has also morphed over time.   This profile was originally created in May 2011 to expand the reach of messages about supporting families (@fsagenda). When the two virtual Facebook communities merged, this twitter profile's identity changed to align with the new initiative around supporting families that was emerging.

- **Google+**

  The Community of Practice for Supporting Families Google+ page was created in May of 2014 to bolster search engine optimization on Google and expand the project's social media presence. It currently has 8 followers and has been viewed over 1,100 times. The small amount of followers can be explained by the newness of this social media channel. Project staff believe the following on this medium will grow as younger parents and professionals learn about the project.

- **Video**

  In addition to the above channels, project videos and media are hosted on Youtube (connected to the CoP Google+ Profile) and Vimeo.

- **Mailing List**

  The Supporting Families mailing list was established in May of 2011 and currently has 331 subscribers. The mailing list was launched a result of the National Agenda for Family Support initiative that grew out of Wingspread as a way for to facilitate the dissemination of the Wingspread report and for people to stay connected to the movement for supporting families. Each subscriber on the list signed up voluntarily for the mailing list initially at the familysupportagenda.org website and now on the CoP website and social media channels.

LifeCourse Toolkit Development and Dissemination

During Year Two of the project, there was an emphasis on developing tools and making them available to assist in operationalizing the concepts of the LifeCourse Framework. The LifeCourse Toolkit was developed by a workgroup, formed in January 2014, with members representing multiple service coordination (case management) and service agencies from around the state of Missouri. The focus of the workgroup was to develop strategies and tools to assist in a life planning process with individuals and families. A life plan is more than just a service plan - it encompasses having a vision for the future, and helps families and individuals explore ways to work toward achieving the vision. Tools for service coordinators were created to assist with planning and creating quality life plans for those they serve and accessing a variety of integrated supports. Service coordinators around the state assisted with creating, piloting, and finalizing the LifeCourse tools.

While professionals helped develop the Toolkit, it can be used by anyone including family members or individuals with a disability. The LifeCourse Toolkit was developed to help individuals with disabilities and families at any age or stage of life think about what they need to know, identify how to find or develop supports, and discover what it takes to live the lives they want. Individuals and families may focus on their current situation and stage of life but may also find it helpful to look ahead to start thinking about what they can do or learn now that will help build an inclusive and productive life in the future. The Toolkit is designed to assist any citizen with a disability think about their life, not just individuals known by the service system. The toolkit was initially developed with people with disabilities in mind, however, it is designed universally and could be used by any family making a life plan, whether or not they have a member with a disability.

The toolkit was first developed in Missouri but is now being used around the nation. Participating Community of Practice states are joining the workgroup remotely and providing input on tool development and how to best use these tools with self-advocates and families. The following tools are currently available for use and can be found on the website at: www.supportstofamilies.org.

Tools for Learning and Understanding the LifeCourse Framework

- **Charting the LifeCourse: Experiences and Questions**
  This booklet helps individuals and families know the questions to ask and things to think about throughout the life course, in order to have the experiences that lead to the good life that they envision.

- **LifeCourse Foundation: Guiding Principles**
  This tool explains the guiding principles and core beliefs of the LifeCourse Framework. It can be used to help someone who is unfamiliar with the LifeCourse Framework understand the basics.

- **Uncharted Possibilities**
  This tool helps individuals and families look at a variety of supports including those that are traditional or historic, but may not be preferred by the next generation (charted), known and tried, but not necessarily the norm (slightly charted), and others that are new or unfamiliar to individuals, families and professionals, but that are more likely to lead to inclusive lives (uncharted). Use as a guide to generate ideas when working with the Vision and Planning Tool.

- **Integrated Supports Worksheet**
  This tool helps families and individuals think about how to work in partnership to support their vision for a good life. Use as a guide to generate ideas when working with the Life Supports Mapping Tools.

Handouts that Supplement the LifeCourse Tools

- **Point in Time – Transition**
  This short four page guide can be used with youth and parents of youth who are nearing or have reached transition age begin to think about aspects in each of the life domains that will be important in the transition from school to adult life. It includes questions to ask and options to consider and discuss with transitioning youth to move toward a vision for a good life as an adult.

- **LifeCourse Infographic**
  This handout is a visual representation of the LifeCourse Framework guiding principles. It pairs best with a presentation or professional who knows the framework well and is able to answer any questions. For a full explanation, the LifeCourse Foundation document should be used.

Tools for Planning with the LifeCourse Framework

- **Life Trajectory Worksheet: Individual and Family**
  This tool can be used to help individuals and families think about what a good life means to them, and identify what they know they don't want. The space around the arrows can be used to identify current or needed life experiences that help point the trajectory in the direction of the good life vision. Charting the LifeCourse: Life Experiences and Questions booklet can be used along with this tool to help generate ideas.

- **Tool for Developing a Vision: Individual and Family**
  This tool is to help families of all ages – those with a very young child, or an adult, develop a more specific vision for their lives. This tool also helps families narrow down what life domain they will start with by rating what is most important to them in their lives right now.

- **Life Supports Mapping Tool: Life Stages**
  This tool relates to supports and services in the current stage of life and the future that will move individuals closer to their "good life" goal. Use the Integrated Supports tool to help generate ideas for a variety of sources of support.

- **Integrated Services and Supports**
  This tool will help families and individuals think about how to work in partnership to support their vision for a good life.

Second Annual Gathering

In May of 2014, the second national meeting of the Community of Practice was held in Kansas City with all six participating states (including Missouri as the demonstration state), as well as project management staff and national partners. The group spent two days together learning about what the participating states had accomplished over the past year, and hearing from a national expert around innovation.

Presentations at the annual meeting included:

- **Opening Remarks** – Commissioner Bishop, Administration on Intellectual and Developmental Disabilities
- **Discussion on Evaluation** – John Agosta, Human Services Research Institute
- **Key Note Address – Creating Blue Space: Fostering Innovative Support Practices** – Hanns Meissner, author of *Creating Blue Space,* presented ideas related to creating space for innovation to occur on multiple levels.
- **National Partner Perspectives** – Kathy Brill – Parent-to-Parent USA, Katie Arnold – Sibling Leadership Network, Donna Meltzer – National Association of Councils on Developmental Disabilities, Liz Hecht – Waisman Center, Cathy Enfield – Self-Advocates Becoming Empowered, Kim Musheno – Association of University Centers on Disabilities.
- **State reports** – Members of state teams reported on state activities and targeted areas for the upcoming year.

The second day of the annual meeting was spent learning about some of the specific systems change strategies around supporting families that Missouri has implemented over the last few years that align with the LifeCourse Framework. State team members also completed an exercise to identify and prioritize future efforts.

State Activities

Connecticut

The state team in Connecticut continued to focus efforts on framing the issues related to supporting individuals and families through the lens of the LifeCourse Framework. To achieve this goal, they engaged in the following activities:

- Created and disseminated a handout titled *Shared Responsibility*
- Presented to several groups within state government, as well as community and advocacy, and family organizations.
- Used the framework when working with new or younger families to explore possibilities, aspirations and expectations.
- One of the ten Community of Practice committees was formed specifically to develop communication efforts.

New positions were added, in some cases by reallocating positions, to build infrastructure within the service system that align with the framework, including:

- Family Youth Coordinator
- Increased number of transition advisors
- Self-determination/employment direct service positions
- Community of Practice Intern

The team is exploring options around technology as a form of support as well as building a web-based networking tool to connect individuals with disabilities with needed supports (modeled after Tyze http://tyze.com/).

Similar to other states in the Community of Practice, the Connecticut team is exploring issues around access to services and experiences at the "front door" and those who are not eligible for services. Strategies include implementing intake procedures related to the additional areas people can access supports (not only paid supports).

There has also been a focus on building alliances and collaborations beyond the developmental disabilities service system.

As a way of implementing the LifeCourse concepts related to helping individuals and families create a vision for the future, the CoP Team has been working to connect with existing training and technical assistance efforts around person-centered thinking for individuals, families and service agencies.

District of Columbia

During Year Two, the District of Columbia Community of Practice team continued to engage in leveraging opportunities to improve supports to families presented by the major systems reform efforts underway in this jurisdiction. For example, a renewed effort around the Developmental Disabilities Reform Act and the development of an Individual and Family Supports Waiver will greatly impact the future service system in D.C. and CoP team members have contributed critical input regarding the need for coordinated lifespan supports for all people with DD.

The current system in DC serves only adults who qualify for intellectual disability services and the CoP provides a way for government, community-based organizations, and family leaders to come together and plan for expansion of supports for people with DD across the lifespan. The structure of the D.C. team includes representation from a range of community and advocacy organizations with a vested interest in supporting families and individuals with intellectual and developmental disabilities.

In order to enhance peer support opportunities, they are launching a Parent-to-Parent Chapter. To work toward this goal, the team has engaged in the following activities:

- Collaborating with Health Services for Children with Special Needs
- Connecting with the National Parent-to-Parent organization
- Planning community meetings to discuss the development of a Parent-to-Parent chapter

The team has also focused on building on existing person-centered thinking and levels of change strategies that have been implemented in D.C. over the past few years throughout not only the DD agency, but the entire IDD support and service delivery system. Activities included:

- Using person-centered thinking tools and skills with the state team to help families envision success, identify changes that are needed at all levels, and create a shared responsibility for making change.
- Implementing PCT tools and skills (Like and Admire, Good Day Bad Day, etc.) into the UCEDD parent training on End of Life planning to help families understand that Future Planning begins with documenting and communicating to let future caregivers know about their child as a person, not as a person with a disability.

To support the meaningful participation of family members and self-advocates in system change activities, DDS was successful in establishing statutory authority to issue stipends to cover time, travel, and child care reimbursement in order to help defray their costs.

Missouri

In Year Two, the Missouri Community of Practice team continued to work to implement the LifeCourse framework in the Division of Developmental Disabilities, with significant representation of DDD staff on the CoP leadership and full state team, and key staff working to implement practices within their focus areas.

Several workgroups were formed that included:

- **LifeCourse Tools:** Develop and pilot LifeCourse tools and accompanying website for individuals and families that will evolve into a toolkit that professionals will use when working with individuals and families.
- **Peer Support Network Strategies:** Focus on a statewide strategy for connecting and enhancing peer support for families across Missouri. Effort lead by Family-to-Family and looking at emotional peer support as well as life navigation peer support and means to support and sustain local entities to provide this service.
- **LifeCourse Strategic Thinking Tools for Organizations and Systems:** Finalize and disseminate LifeCourse materials currently being piloted by several organizations and systems to think about policy and practice changes.

Members of the state team worked with the Missouri Developmental Disabilities Council to align the goals of the Council's five year plan with the LifeCourse Framework.

Missouri State Employment Leadership Network (SELN) and Show Me Careers partnered with Family-to-Family LifeCourse Network to design transition tools for families based on the LifeCourse Framework that are being incorporated into other statewide activities and agencies. The Bureau for Special Health Care Needs is disseminating materials to case managers and families receiving their services.

As part of a communication strategy, videos of individuals with developmental disabilities and their family members describing what a "good life" means to them were created and disseminated via web-based platforms.

Oklahoma

The Oklahoma Community of Practice team continued to build on the opportunities to improve supports system wide in Year Two through the Governor's Blue Ribbon Panel. Preliminary recommendations generated by the Blue Ribbon Panel align with two of the strategies to support families identified in the LifeCourse Framework – Strengthen Information Access and Provide Resource Navigation and Improve Inter-Agency Service Coordination. A primary focus of the Blue Ribbon Panel has been on developing strategies to reduce the number of people waiting for services in Oklahoma. Members of the national project team were able to provide assistance with restructuring the way the Panel was organizing the waitlist based on the data they were collecting on those individuals.

During Year Two, they expanded the state team to include representatives from Children with Special Health Care Needs and the Family-to-Family organization.

The state team focused on creating a knowledge base among stakeholders regarding the LifeCourse Framework. They have worked to incorporate the LifeCourse principles into the "On the Road" conferences in order to expand the message to rural areas in Oklahoma.

Through work of the Community of Practice team, LifeCourse planning concepts and tools have been utilized with the following groups:

- Partners in Policymaking
- Youth Leadership Forum

Similar to other states in the Community of Practice, the Oklahoma team identified targeting efforts to improve the intake experience for individuals and families. DDS worked with intake staff to develop a structured interview format that incorporates a few guided questions based on the LifeCourse principles.

Members of the CoP team were involved in the planning of the annual Joining Forces Conference that brings together an array of individuals, families, and professionals. They used this opportunity to discuss the LifeCourse Framework.

Tennessee

The Community of Practice team in Tennessee has worked to establish connections with existing initiatives that complement efforts to support families particularly around addressing the waitlist for services, employment for people with IDD, and provider qualifications. They have made connections with other entities to focus on integrating services across the lifespan including the Governor's Children's Cabinet and the Tennessee Parent-to-Parent.

They worked to improve the first point of contact individuals and families have with the state DD agency by training staff and revising procedures to ensure that it is a meaningful encounter, even if they are not eligible for (or able to access) waiver services at the time. They completed a LEAN event to streamline the intake process to allow intake staff to spend more time with families and individuals.

To share information about the LifeCourse framework and gather input from stakeholders, in Year Two the Tennessee team held a series of "Lunch and Learn" events. They also developed and disseminated the Tennessee version of the resource folder.

They have also worked to provide meaningful information and support to those on Tennesee's lengthy waiting list for services – some families have been waiting many years. The intention is to "Repurposing the interaction" between DIDD case managers and those on the waiting list; and help staff provide families with anticipatory guidance and discussions about integrated supports to help prevent crisis.

Washington

The state team in Washington focused on connecting with system-wide redesign efforts including the development of an Individual and Family Services Waiver Program and the implementation of the Community First Choice Option. These efforts were already underway in Washington as a way to improve the system of care for individuals with IDD and to reduce the waitlist.

They worked to reframing state services by taking the opportunity to evaluate the services provided by the State and whether they benefit or hinder families and individuals in the community. To gather input from indivduals and families, they spent time planning for and conducting a number of "Listening Tours" across the state.

To communicate with individuals, families, and the broader community, the Washington state team has used opportunities to share informaiton about the LifeCourse Framework and Community of Practice activities through the "Informing Families, Building Trust" website and listserv. They also developed and disseminated the Washington version of the resource folder.
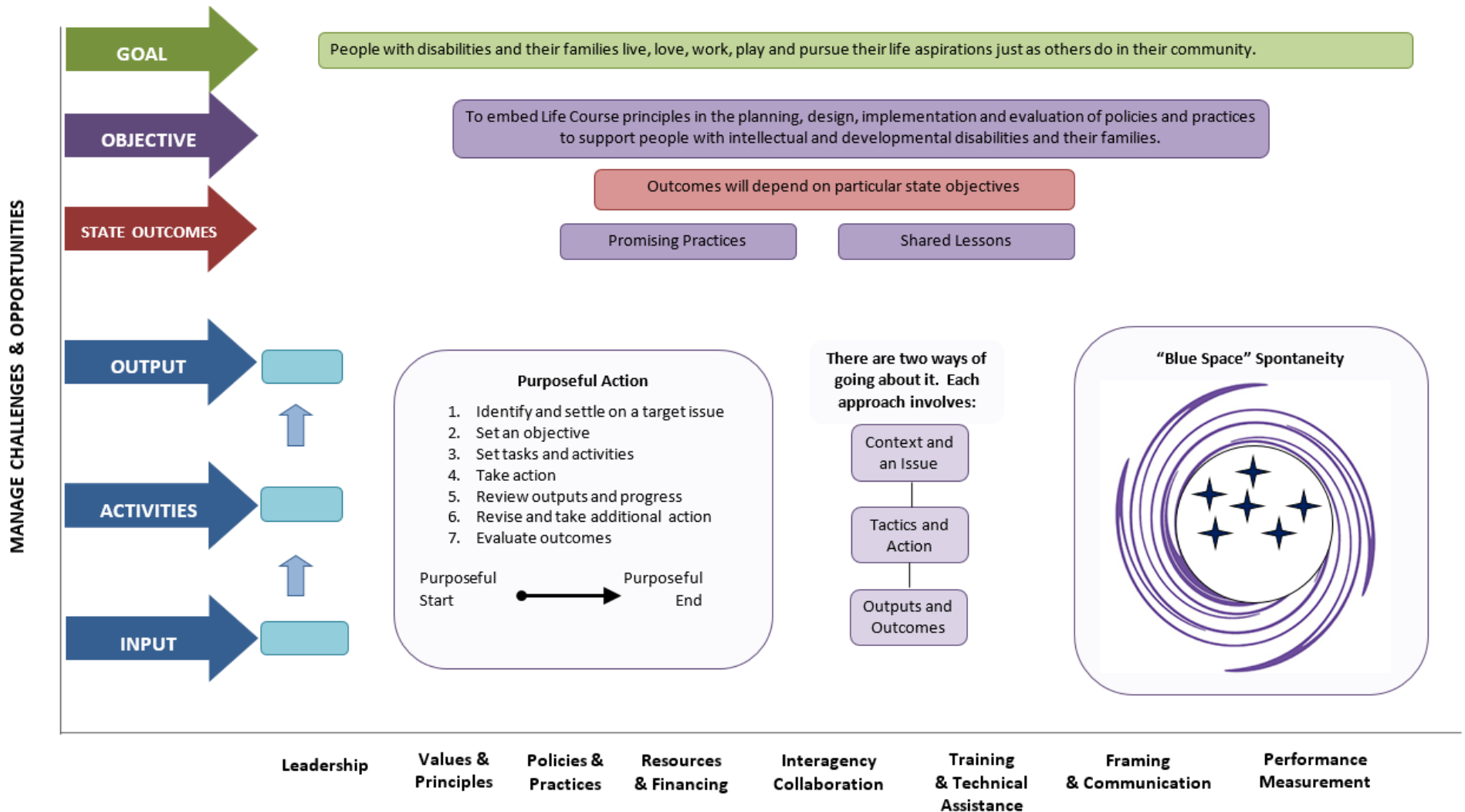
Evaluation

In Year Two, the evaluation plan evolved to respond to the approaches that participating states appeared to be employing. The national project team experienced difficulty documenting discrete practices that were applied consistently within states. The overall objective was changed to capture the true objective of the initiative, which is to: ***Embed LifeCourse principles in the planning, design, implementation and evaluation of policies and practices to support people with intellectual and developmental disabilities and their families.*** Components were added to the logic model framework to describe the way in that states were engaging in activities, which included both purposeful actions, as well as spontaneous actions, that may have been a result of taking advantage of unforeseen opportunities or exploratory activities and then gauging the effectiveness. Figure 3 displays the updated logic model.

Following the annual meeting, participating states began submitting monthly written reports to the national project management team. These reports served as one way to collect information regarding the types of activities that the state teams are engaged in to further the goals of the project. Members of the national project team also spoke with each state facilitator to review and activities described in the state reports and gather any additional information. These data were then compiled, categorized, and coded according to (a) logic model components, (b) systems drivers, (c) practices to support families, (d) government or non-government, and (e) Life Course principles. Each variable was then depicted graphically to identify areas where the participating states were focusing their efforts. This information was used to compare efforts across states, and track trends or changes in the nature of the activities over the course of the project. Table 2 shows the coding key that includes the items within each variable and a definition. The key is in draft form, and as the project progresses this tracking mechanism will be further refined.

Figure 3: National Community of Practice
Evaluation Logic Model, 2014

MANAGE CHALLENGES & OPPORTUNITIES

GOAL
People with disabilities and their families live, love, work, play and pursue their life aspirations just as others do in their community.

OBJECTIVE
To embed Life Course principles in the planning, design, implementation and evaluation of policies and practices to support people with intellectual and developmental disabilities and their families.

STATE OUTCOMES
Outcomes will depend on particular state objectives

Promising Practices

Shared Lessons

OUTPUT

ACTIVITIES

INPUT

Purposeful Action
1. Identify and settle on a target issue
2. Set an objective
3. Set tasks and activities
4. Take action
5. Review outputs and progress
6. Revise and take additional action
7. Evaluate outcomes

Purposeful Start → Purposeful End

There are two ways of going about it. Each approach involves:

Context and an Issue

Tactics and Action

Outputs and Outcomes

"Blue Space" Spontaneity

Leadership | Values & Principles | Policies & Practices | Resources & Financing | Interagency Collaboration | Training & Technical Assistance | Framing & Communication | Performance Measurement

Table 2: Key for Coding National Community of Practice Activities

	Variable A – Logic Model Components	
1	**Inputs**	Resources available (e.g., money, staff, equipment).
2	**Activities**	Activities that the state team engages in.
3	**Outputs**	Products of the activities (e.g., number of folders produced, people trained).
4	**Outcomes**	Changes or benefits that result from the efforts.
	Variable B – System Drivers	
1	**Leadership**	Committed leaders with a degree of influence in the state are leading the charge.
2	**Voice of Self-Advocates & Families**	Individuals and their families are involved in the activity or policy decision.
3	**Guiding Principles & Values**	A set of values or principles is in place and guides the work.
4	**Framing & Communications**	A clear and consistent message is developed and conveyed. A particular or range of audiences is targeted and receives information.
5	**Collaboration & Partnerships**	Collaboration among state agencies, community organizations, etc. is built or enhanced.
6	**Training & Technical Assistance**	Training or technical assistance is provided in relation to new policies or practices.
7	**Space for Innovation to Occur (Blue Space)**	Opportunity or mechanisms that allow for creation and development of new and innovative practices
8	**Policies & Directives**	Policies and/or Directives are being developed or implemented.
9	**Infrastructure**	The necessary components to sustain policies or practices are being built or are in place.
10	**Quality Assurance & Outcome Data**	Information is collected and used to measure outcomes and monitor quality.
	Variable C – Practices to Support Families	
1	**Discovery & Navigation**	Information, education, and training on best practices within and outside of disability services, accessing and coordinating community supports, and advocacy and leadership skills.
2	**Connecting & Networking**	Connecting and networking a family with other families, including parents with disabilities, self-advocates and siblings, grandparents and others for mutual support.
3	**Goods & Services**	Services and goods that are specific to the daily support and/or care-giving role for a person with a disability, such as planning for current and future needs, respite, crisis prevention and intervention, systems navigation, home modifications, and health /wellness management.
	Variable D – Government vs. Non-government	

0	**Government**	The emphasis is coming from or impacting primarily government related policies or practices (e.g., development of HCBS service definition).
1	**Non-government**	The emphasis is coming from or impacting primarily the community sector (e.g., training for local hospital physicians on responding to the needs of individuals with IDD and their families across the LifeCourse).

Variable E – LifeCourse Framework Principles		
1	**All people with DD**	This includes those receiving formal state DD services, known to the state DD agency but not receiving services (wait list, TCM only), and not known to state DD service system.
2	**Family**	The role of the family and impact on the family are considered including: • Family defined by the individual or legal/blood related parent • All family member relationships considered (parents, siblings, etc.) • Family cycle recognized • Reciprocal role of member with disability in the family recognized
3	**Life Stages & Trajectory**	Addresses one or all of these stages: • Prenatal/infancy; early childhood; school age; transition; adulthood; and aging Considers the response to the current need as well as the impact on the future.
4	**Life Domains & Outcomes**	This includes a focus on life experiences and assists the individual with the disability and/or their family to develop a vision or aspirations for a quality of life. Considers one or all of the following life domains: • Daily living/Employment; Safety and Security; Community Living; Healthy Lifestyle; Social & Spiritual.
5	**Integrated Delivery of Supports**	Supports are integrated across one or all of these types of support: • Personal or Family Strengths and Assets: Own skills (drive a car, stay at home by self), family (owns the home) • Technology: Technology as the "support" or to assist in a life domain • Community Supports: All community members can access, even if it requires payment • Peer Support: Provided by a family, friend or other relationship (coach, teacher, etc.) • Eligibility Based Supports: Public supports that require disability or financial eligibility (Medicaid, HUD, VR, etc.)

Lessons Learned

In Year Two, the national project team and participating states continued to build on and refine the LifeCourse Framework. Members appeared to develop a greater understanding of the principles of the LifeCourse Framework and how to begin to apply this to existing practices and initiatives, identify gaps in service models, and develop and implement new strategies to address those gaps. This was evidenced in how state teams planned for and accomplished particular activities. For example, many state teams attempted to include and partner with community outside the DD agency in order to integrate supports across the life span. Many states described organizing information or planning events according to LifeCourse principles and materials such as the graphic representations of the life span and community life icons. Many of the states also invested in developing and implementing tools to assist front line staff and case managers or support coordinators in their role with assisting individuals and families to envision and plan for the supports needed to achieve a good life as they define it.

State teams identified a need for more technical assistance as they move forward with their activities. The national project team implemented scheduled monthly meetings with each of the state facilitators to provide technical assistance.

One of the challenges this year was to assess the degree of influence or impact that state teams had on existing system-wide initiatives that were well underway at the onset of the Community of Practice project. Some states reported that they encountered challenges when working with state leadership to make the connection between improving efforts to support families and, for example, elimination of waiting lists or closing institutions.

Next Steps

As the Community of Practice on Supporting Families proceeds, state teams will work to set goals and objectives that are relevant to their state and consistent with the Life Course Framework. The progress and lessons learned throughout will be tracked on the state level and at the national Community of Practice level. The project team, with input from participating states, will identify and provide additional learning opportunities about areas of interest to advance the work within and among states. Along the way, other states will have the opportunity to learn about the activities of the Community of Practice through the website, project materials, and presentations.