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

Year One Report

September 2014

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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

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Introduction

In October 2012 the US Administration on Intellectual and Developmental Disabilities (AIDD) awarded funding to the National Association of State Directors of Developmental Disabilities Services (NASDDDS), the Institute for Human Development at the University of Missouri – Kansas City (UM-KC), and the Human Services Research Institute (HSRI) 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.

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 One 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 provide a description of the activities and achievements associated with the first year of the project. What follow is: (a) a description of the COP's design and purpose, including summaries of the project's conceptual underpinnings related to systems change and the Life Course framework, (b) Year One activities, (c) lessons learned, and (d) next steps.

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[1]   Hecht, E., & Reynolds, M. (2012). *Building a National Agenda for Changing Systems for Supporting Families with a Member with a Disability*. Washington DC: Administration on Intellectual and Developmental Disabilities.

Community of Practice Design and Purpose

A community of practice is a learning environment for an intensive exploration into current policy, practices, trends, and barriers. The key to a community of practice is understanding that the sum of the community knowledge is greater than the sum of individual knowledge. This model was chosen as the way to explore principles, practices, and data indicators related to supporting families for a variety of reasons including:

> The key to a *Community of Practice* is understanding that the sum of the community knowledge is greater than the sum of individual knowledge.

- Connecting people who may have never had contact;
- Providing a shared context for people to communicate and to share information;
- Enabling dialogue between people wishing to solve the same types of problems;
- Stimulating learning by serving as a vehicle for communication, mentoring, coaching, or self-reflection;
- Capturing and diffusing existing knowledge;
- Introducing collaborative processes and encouraging the free flow of ideas and information;
- Helping people organize around purposeful actions; and
- Generating knowledge

Specifically for this project, five states were selected to participate in the Community of Practice with the intention of sharing the lessons learned throughout the nation. In addition to the five states, Missouri joined as the demonstration state for the project. Each state formed a team that was facilitated jointly by the state Agency on I/DD and the state Council on Developmental Disabilities with additional membership from self-advocacy and family organizations, university, education, aging and other organizations with a vested interest in supporting families.

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. The strategies and guiding principles specific to supporting families presented in the Wingspread Summit report – *National Agenda for Supporting Families with a Member with Intellectual and Developmental Disabilities* – were also incorporated into the systems change framework.

There are several components of the systems change framework and each component works with the others to drive systems change. The components include catalysts, leadership and principles, and a set of performance indicators. For this project, the indicators are split into two categories: state systems and service innovations. Indicators related the state systems category include policies and goals, financing, training and technical assistance, and outcome data. Indicators related to the service innovation include family specific strategies, implementation of service delivery, and the role of support coordination. In order to achieve the goals of systems change, there must also be collaboration across agencies and organizations that have a vested interest in supporting the wellbeing of individuals with IDD and their families. This systems change framework promotes the outcome of a good quality of life for people with disabilities.

Framework for Supporting Families

The LifeCourse framework for supporting families used by the Community of Practice was developed by the Missouri Family to Family (MOF2F) and provides a guiding ideology and vision for any effort to develop or improve supports for families. It is a useful tool for professionals, families, and self-advocates. It uses plain language, and is created in such a way that anyone could use it, not just the disability field. For those reasons, leaders and agencies around the nation have started using the framework to organize their ideas, actions and communications.

The initial framework was created with the assistance of the Missouri Family to Family Network with involvement from a stakeholder group made up of self-advocates, family members, and professionals. As the framework has been introduced and utilized by the Community of Practice it has continued to evolve.

The image on the right is a first draft of a visual representation of this framework used in Year One of the project. In a person-centered system, the individual is in the center, and they are surrounded by their family and network. A principle of this framework is that the family and network are defined by the individual and do not necessarily include the traditional nuclear family unit. The network can include extended family, neighbors, coworkers, etc. In order for an individual, their family, and their network to have the most integrated life in the community, they may need support. There are three strategies for these supports including Discovery and Navigation, Connecting and Networking, and Goods and Services.

Supporting Families of Individuals with I/DD Throughout the Life Course
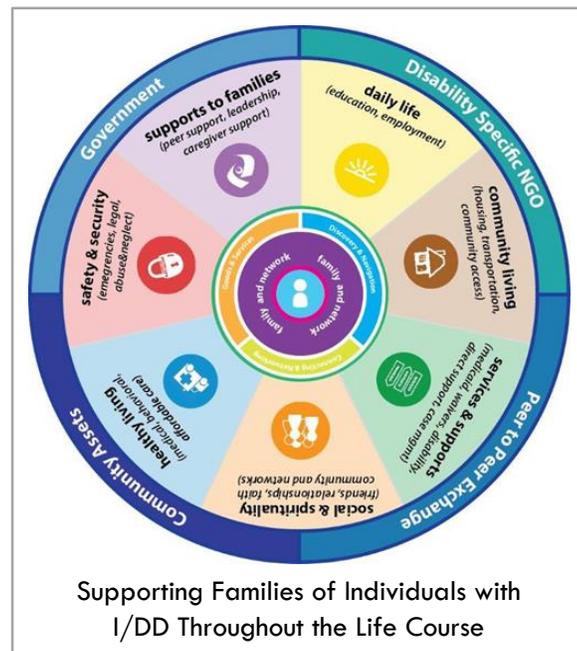
Strategies for Supporting Families

Discovery and Navigation	Connecting and Networking	Goods and Services
Information, education, and training on best practices within and outside of disability services, accessing and coordinating community supports, and advocacy and leadership skills.	Relating with other families, including parents with disabilities, self-advocates and siblings, grandparents and other guardians for mutual support.	Specific to the daily support and/or care-giving role for the person with I/DD, such as planning for current and future needs, respite, crisis prevention and intervention, systems navigation, home modifications, and health/wellness management.

The life domains presented in the framework are not disability specific; they apply to any individual with or without disabilities. The support strategies can be utilized in any one of the life domains. No single domain is any more important that the other. They are all aspects of a good quality of life. A description of the domains are included in the table on the below.

LifeCourse Framework Life Domains

	Daily Life	What a person does as a part of everyday life; school, employment, volunteering, communication, routines, life skills.
	Community Living	Where and how someone lives; housing and living options, community access, transportation, home adaptations, and modifications.
	Social and Spirituality	Building friendships and relationships, leisure activities, personal networks, and faith community.
	Healthy Living	Managing and accessing health care and staying well; medial, mental health, behavior, developmental, wellness, and nutrition.
	Services and Supports	Service and supports for individuals and families, both funded systems and natural supports; personal/family financial.
	Safety and Security	Staying safe and secure; emergencies, well-being, guardianship options, legal rights and issues
	Supports to Families	Support for families and individuals; peer support, self-advocacy, family education.

Finally, the framework presents four primary avenues for support that individuals and families can access including: a) community assets, b) peer-to-peer exchanges, c) disability-specific non-governmental organizations, and d) state government. In order to promote the full inclusion and membership of people with IDD in their communities, the framework encourages individuals, families, and those who support them to first think about and access supports available to all members of the community and move through the progression of options ending with state-funded services.

Year One Activities

State Application and Selection

The request for proposals to participate in the national Community of Practice was distributed nationally with a submission deadline of April 12, 2012. Letters of support from self-advocacy organizations, family organizations, or other entities involved with supporting families or individuals with I/DD were encouraged. Requirements for participation in the Community of Practice were included in the application packets.
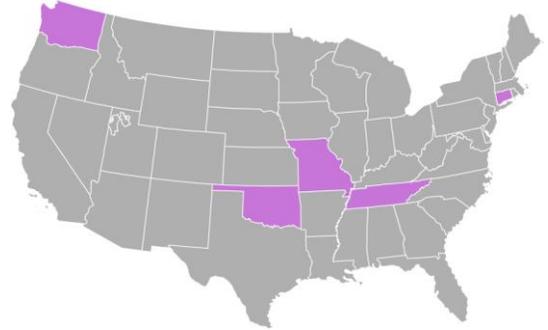
The application specified that it had to be submitted jointly by the state Agency on I/DD and the state Council on Developmental Disabilities. Other information in the application packet included the following:

- Selected states will receive $5,000 in year one and $10,000 in years two through five.

- Technical support will be provided by the managing partners and will include annual on-site meetings in each state.

- It will require a commitment of time and resources dedicated to evaluating, prioritizing and implementing policies and practices that will facilitate supporting families.

- At a minimum, states will need to identify a Lead Facilitator, create a Community of Practice Management Team, participate in monthly CoP calls and attend annual meetings with all CoP members.

Fifteen states applied to participate in the project and the five states that were chosen included: Connecticut, District of Columbia, Oklahoma, Tennessee, and Washington, with Missouri acting as a demonstration state.

Overview of Participating States

The following table provides an overview of the five Community of Practice states, based on information provided in their applications and organized by the systems change components.

Table 1: Overview of Community of Practice States by Systems Change Component

Systems Change Component	State Descriptions
Leadership	• Four of the states; DC, Connecticut, Oklahoma, and Tennessee are Employment First states • All five states have strong governmental support, from things like the Governor's conference on DD, to having people with disabilities and their families active on boards.
Service Innovation	• Connecticut, Oklahoma, Tennessee, and Washington offer self-directed supports options. • Connecticut, Oklahoma, DC, and Tennessee have Partners in Policymaking programs. • All five states have at least one organization in their state that assists with peer-to-peer mentoring • Washington, Oklahoma, and Tennessee have waivers that allow for paid family care givers
Principles	• All five states value person-centered thinking, some have provided more training than others. • All five states involve individuals with disabilities and family members in policy making. • All five states have implemented person-centered planning processes.
Interagency Collaboration	• All five states have examples of the State Agency and the DD Council collaborating for projects. • Oklahoma works very closely with its UCEDD. • Tennessee and Washington have recently had in-state collaborations to host conferences.
State DD Systems	• All five states support a self-advocacy group. • All five currently provide some type of family support services, examples include: Home modifications, respite, cash subsidy, adaptive equipment, transportation, case management, money follows the person, family training, supported employment, emergency services, etc.

First Annual Gathering

In June of 2013, the first 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 and a half days together learning about the Life course framework, and preparing to establish priorities to best support families back in their states.

Human Services Research Institute (HSRI) also presented data related to Medicaid-funded supports including residential placements, services, and expenditures. Data were presented to depict national trends as well as specific data related to each of the participating states.

State Kick-Off Events

Following the national kick-off meeting, each of the five states conducted a local kick-off event to engage stakeholders in their states. Project management staff traveled to all five state to and assist with the kick-off events. Each state employed a slightly different approach and the following presents an overview of each state's event:

- **District of Columbia** — Convened a small group of key players in the DC area. Attendees reported they had a good experience at the kick-off. Decided to start work by hosting community conversations in DC, focusing on family networks as the project begins.

- **Connecticut** — Hosted a larger kick-off event with close to 200 on the first day and 40 on the second day. Talked about big picture of family support. Broke into small groups. People signed up for various committees to stay involved and do the work. Currently there are 10 committees with 10-15 people on each committee. Focus on keeping everyone involved and keeping the momentum going.

- **Tennessee** — Engaged a targeted group for the kickoff. Did an overview of the project and the supporting families using the Life course framework. Focusing on the idea of trajectory, and how to make a person's trajectory go toward a good community life. Second day of the kick-off was spent planning and moving forward.

- **Oklahoma** — The project management staff met with members of the core workgroup. Working to change thinking in their state. Practices and thinking around the pockets of excellence are not being moved across the state or into the state agencies. Had one day with case managers from DD agency.

- **Washington** — The first day of the kick-off had 60-70 stakeholders in attendance of the day-long session. Intentionally invited a cross section to participate including families, younger kids, older adults, people that were newer to the system, efforts to reach new people, beyond those who usually attend. Attendees appeared to appreciate the framework. Afternoon roundtable discussions related to impacts on families, dynamics change over the life course, response to families. Second day, state team, went over round table discussion results. Convening listening sessions around major themes that seem to be impacting families.

Communication Structure

States involved in the Community of Practice receive technical assistance from the project management staff via regularly scheduled conference calls. State facilitators are also encouraged to reach out to project staff if they have questions or encounter challenges. Monthly teleconferences convening all the CoP states and project management staff are held to share learning across states. Periodically, additional webinar training opportunities are provided to enhance learning across the participating states related to a particular topic or innovative practice in supporting families.

Evaluation

The evaluation plan for this Community of Practice utilizes strategies based in part on a Developmental Evaluation framework. The objectives and activities undertaken in each of the states are evolving over the life of the project. This makes it difficult to measure fidelity to a particular model or practice that is employed consistently over the course of the project to achieve measureable outcomes. The basic evaluation plan uses a logic model framework with goals, objectives, outputs, activities and inputs for each of the indicators of systems change including Leadership, Training & Technical Assistance, Interagency Collaboration, Performance Measurement, Resources & Financing, Framing & Communication, Supports to Families, and Values & Policies. Goals related to the Community of Practice as a whole as well as state specific outcomes are included. As states begin to target specific areas for improving supports to families, their progress will be tracked using this model. The graphic below illustrates the logic model.
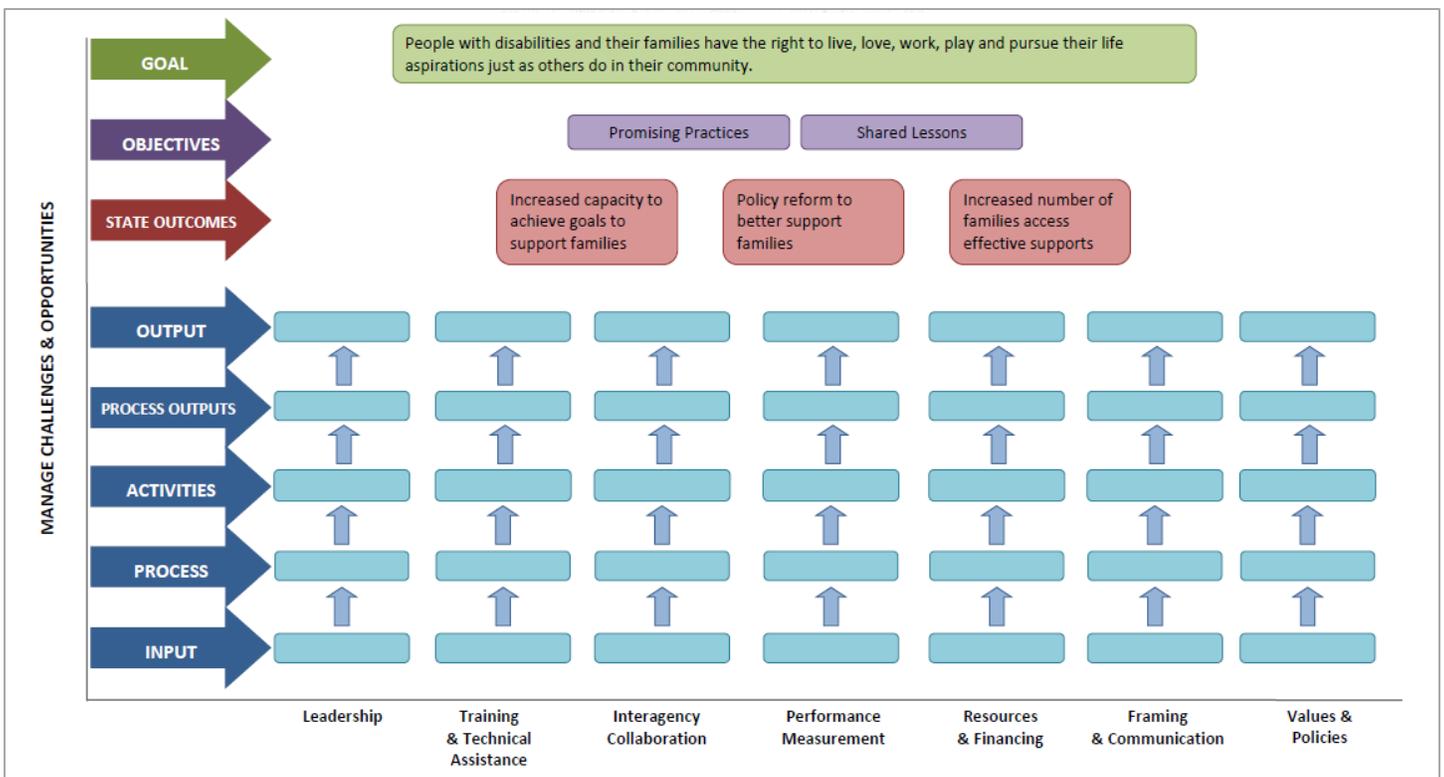
Lessons Learned

During the first kick-off event in Kansas City, the Life course framework and goals and objectives of the Community of Practice were explained, and many attendees reported that they would need to spend time processing the information and applying this new way of thinking to the strategies they employed in their states. Many of the principles embedded in the framework require thinking beyond the limits of a service life for individuals with disabilities and their families to supporting real lives in the community. While attendees widely accepted the Life course framework as a guiding theoretical framework, they understood that the work ahead entailed the challenging task of operationalizing the theory into practice.

In order to target a starting place, state teams were encouraged to identify strategies and activities that they could exert immediate influence and achieve successful action. Many states chose to capitalize on activities or initiatives that were already underway in their state to support families and infuse the values of the Life course framework to the existing work.

Many state teams identified that they needed to start by sharing the message of the Life course framework. States varied in their communication strategies from targeting a broad range of stakeholder groups to working strategically within their own agencies and across partner organizations. Some state teams chose to model their outreach materials based on tools and products that had been developed in Missouri. For example, some states chose to adopt the Missouri resource folder for use in their state. State teams learned that the process of creating the resource folder and exploring channels for distribution were equally as important as the final product.

The project team attended each states' kick-off meeting and spent time in most states completing a trajectory exercise that provided a practical application of the Life course framework. This proved to be a very useful process and based on the response from state teams, the project team created a tool to guide others through the exercise.

Next Steps

As the National Community of Practice for 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 the 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.