Charting the Life Course for Persons with IDD and their Families: Moving from Principles to Practice

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Executive Summary

In the fall of 2016, Pennsylvania joined the National Community of Practice for Supporting Families of Individuals with Intellectual and Developmental Disabilities (CoP), which started with five states and the District of Columbia in 2013 with funding from the U.S. Administration on Intellectual and Developmental Disabilities (AIDD) and has since expanded to include 17 states. The early adopting states worked to develop a framework for systems change to enhance support to all persons with intellectual and developmental disabilities (IDD), including their families and caregivers. Envisioning a new approach to supporting families, who in turn provide lifelong supports to their loved ones with IDD, was critical given the challenges that these individuals and their families currently face.

The resulting approach known as the Supporting Families LifeCourse Framework consists of a set of guiding

principles and components necessary to establish as well as scale-up innovative approaches across a system. The participating states found that the framework offered a process to arrive at innovative, values-driven solutions to common issues that families experience at any stage of life. The guiding principles resonated with a broad audience and instigated new partnerships by identifying common goals among entities supporting families across the lifespan. Most importantly, the renewed energy and investment in families invigorated the movement around supporting individuals with IDD and their families to live a life like anyone else.

Setting the Stage

In the United States, approximately 4.7 million citizens have an intellectual and/or developmental disability (IDD).[1] Due to the continued efforts of self-advocates, their families and other advocates, persons with IDD are living, working, playing and contributing to communities across the nation. Key pieces of federal legislation protect and promote the full inclusion of persons with IDD, such as the Developmental Disabilities Assistance and Bill of Rights Act, reauthorized in 2000, which asserts, "disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities..." [2]

In response to changing expectations regarding persons with IDD, an array of government and private supports and services have necessarily evolved. Government institutions (such as schools, health care, long-term services, and vocational rehabilitation), are in a constant state of transformation – moving away from segregated, clinical settings and toward more inclusive structures that support opportunities for persons with IDD to participate fully in all aspects of community life. Organizations are adopting person-centered approaches, employment first initiatives, and quality of life outcomes to meet these expectations. Simultaneously, these systems are responding to increased demand for services, decreased budgets and an overextended workforce.

Amongst these changes, the commitment, resilience, and role of families with a member with developmental disability remains constant. The reciprocal, lifetime bond of loving one another and providing varying levels of support to all its members throughout the lifespan, especially during the early childhood years and as members age, holds true for all families. Families with members with IDD experience the joys and sorrows as any family does; however, there are often additional pressures and demands related to responsibilities for day-to-day caregiving as well as financial, social and emotional stressors that may endure over an entire lifespan.[3] The family fulfills crucial roles in ensuring the quality of life of its members while maintaining the quality and coordination of supports received or needed well beyond childhood years, regardless of whether the person with IDD receives formal services. It is estimated that families provide $335 billion worth of caregiving annually for their members with disabilities.[4,5]

Current Reality for Persons with IDD and Their Families

Data shows a steady increase in both the number and proportion of individuals receiving long-term services and supports while living in the home of a family member, concurrent with the shift away from large facilities to supporting individuals with IDD in the community. From 2000 through 2013, the number of people receiving services at home grew 61%, from 391,859 to 630,367.[6] Of those receiving Medicaid-funded services, the largest publicly-funded mechanism to deliver services to adults with IDD services, about 56% live with families, a percentage that has held steady over the past several years.[7] These services are primarily, if not exclusively, directed at the person with a disability, (i.e., the Medicaid beneficiary) with few supports targeted to the family (e.g., caregiver training, respite, etc.). Individuals with IDD and their families often find that public systems of support can be inaccessible, difficult to navigate and tend to be limited in their capacity to meet the varied array of supports that individuals and families need.

While state IDD agencies serve a significant number of people, these efforts tend to account for only small portion of those with IDD. Thousands of others are on wait lists, receive services elsewhere (e.g., through schools or religious institutions), or receive other government benefits such as Supplemental Security Income. Still others receive no publicly-funded support whatsoever and remain largely unknown to human service authorities. Their needs may be met presently by other means, and/or they may be in need of support but unable to access the assistance they need.

Building on a National Agenda for Supporting Families

In 2011, a group of national stakeholders representing family leaders, self-advocates and professionals came together to develop a new construct for defining and implementing supports and services that would enhance the lives of persons with IDD and their families based on the current reality and expectations. The resulting National Agenda for Supporting Families with a Member with IDD challenged prevailing long-term care systems to reframe their understanding of "family support," and the implications for policy and practice. It also defined supporting families in a manner that focused on the person with IDD while recognizing the vital role of the families and their individual needs for support.

Table 1 highlights key areas proposed in the National Agenda as foundational concepts for supporting families that differed from the field's traditional understanding of family support.

Table 1: Evolving Family Support to Supporting Families

Specifics	*Traditional Family Support*	*Supporting Families*
Who defines?	Defined by service system as a billable service or program with eligibility criteria.	Defined by persons with IDD, families, the disability service system, and other stakeholders that is beyond programs and services.
Who benefits?	Focus on caregiver or parent providing day-to-day for individual in the home.	Focus on family unit regardless of where person with IDD lives. Membership defined by family.
Whose needs are prioritized?	Tension between self-advocacy movement and family support movement.	The new definition recognized the need for self-determination and self-advocacy of individual members of the family, as well as the family unit.
What is the	Crisis, immediate	Focus on preventative, long-

focus?	response.	term futures planning.
What is the goal?	Supporting caregiver in order to decrease demand on long-term services.	Quality of life for person with IDD and his or her family in the community, with supports needed for the best possible life.

Developing a National Community of Practice

Five states including Connecticut, Missouri, Oklahoma, Tennessee and Washington, and the District of Columbia formed the National Community of Practice for Supporting Families of Individuals with Intellectual Disabilities (CoP) in 2013, with support from the U.S. Administration on Intellectual and Developmental Disabilities (AIDD), to begin operationalizing the recommendations set forth in the National Agenda and help inform a cohesive response to current circumstances. The challenge to CoP members was not to design another family support program, but rather to inspire a shift in culture that would permeate systems and shape the future of supports.

The CoP was codirected by key staff members at the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the University of Missouri- Kansas City (UMKC). NASDDDS contributed an invaluable understanding of state systems, and UMKC provided experience working closely with families through managing the Missouri Family-to-Family network. This dynamic – the perspective of the family in tandem with that of the system– was key to fueling the way forward in a productive way.

CoP activities provided multiple avenues for frequent interaction among participants through monthly teleconferences, quarterly webinars, regular phone and onsite meetings with national project directors, and an annual in-person meeting. Project staff also established a website whereby materials could be shared publicly as well as within the membership of the CoP (http://supportstofamilies.org). Through these forums, participants exchanged information, learning and opinions related to specific actions taken to enhance supports to families and other immediate caregivers.

The renewed energy and interest in supporting families sparked by these early adopting states quickly spread. In its fifth year, eleven new states joined the CoP, including Alabama, Delaware, Hawaii, Indiana, Kansas, Kentucky, Maryland, Ohio, Oregon, Pennsylvania, and South Dakota. Their collective mission was to consider how:

- Families are supported in ways that maximize their capacity, strengths, and unique abilities to best nurture, love, and support all individual members to achieve their goals; and

- Individuals with IDD are supported to achieve self-determination, interdependence, productivity, integration and inclusion in all facets of community life.

Developing a Values-driven Framework

CoP participants spent the first year defining principles built on the construct outlined in the National Agenda, which would guide the work of state teams. The principles were developed through an iterative process with stakeholders from the six CoP sites and reinforced with widely accepted concepts, theories and practices from across a number of disciplines, such as the life course health development model, socioecological model, family systems theory, family and person-centered support models, self-determination and social capital.

In addition to the guiding principles, the overall systems framework incorporated fundamental system underpinnings that helped drive more definitive changes based on the needs of both the person with IDD as well as their families. Aspects to initiate and sustain efforts to realign systems of support included catalysts to prompt change, an underlying system infrastructure and drivers to institute exemplary approaches. These components became known as the Supporting Families LifeCourse Framework. Beyond this foundation, the core belief centered on the premise that *all people have the right to live, love, work, play and pursue their dreams in their* *community.*

Table 2 highlights the key principles of the Supporting Families LifeCourse Framework.

Table 2: Supporting Families LifeCourse Framework Principles

Family Systems and Cycles	People exist and have reciprocal roles within a family system, which adjust as the individual members change and age. Individuals and families need supports that address all facets of life and adjust as the needs of all family members change as they age through the family cycle.
All People	All individuals and families, whether they are known to the IDD system and/or receive formal services or not, are considered in the vision, values, policies and practices for supporting people with IDD.
Strategies to Support Families	Supports address all facets of life and adjust as roles and needs of all family members change. Types of support might include discovery and navigation (information, education, skill building); connecting and networking (peer support); and goods and services (daily living and financial supports).
Life Outcomes	Individuals and families focus on life experiences that point the trajectory toward a good quality of life. Based on current support structures that focus on self-determination, community living, social capital and economic sufficiency, the emphasis is on planning for life outcomes, not just services.
	People lead whole lives made up of specific and

Life Domains	integrated life domains that are important to a good quality of life, including daily living/employment, safety and security, community living, healthy lifestyle, social and spirituality, and citizenship and advocacy.
Life Stages & Trajectory	Individuals and families can focus on a specific life stage, with an awareness of how prior, current and future life stages and experiences impact and influence life trajectory.
Integrated Delivery of Supports	Individuals and families utilize an array of integrated supports to achieve the envisioned good life, including those that are publicly or privately funded and based on eligibility, community supports that are available to all, relationship-based supports, technology, and those that take into account the assets and strengths of the individual and family.
Policy & Systems	Individuals and families are satisfactorily involved in policy-making so that they influence planning, policy, implementation, evaluation and revision of the practices that affect them. Individuals and families design and direct the supports they receive to the extent possible with sufficient public funding allocated in ways that are fair to all individuals and families.
Universal Strategies	Individuals and families consider resources available in communities and connections with others as protective factors, identify public and private organizations available to support families, and rely on formal home and community-based services to meet specific needs.

The CoP contributed to the expansion of the Supporting Families LifeCourse Framework by demonstrating its application to enhance supports to families across multiple states. The framework was effective for several reasons: (a) it offered an organizing framework to arrive at innovative, values-driven solutions to common issues that families experience at any life stage; (b) the principles resonated with a broad audience and instigated new partnerships by identifying common goals among entities supporting families across the lifespan; and (c) it invigorated the movement around supporting individuals with IDD and their families to live a life like anyone else.

Reframing the Conversation at All Levels

CoP participants recognized that addressing the needs of families could not exist as a separate initiative apart from larger systems and policy reform; rather, it was necessary to embed the values from the CoP across the system. This presented each site with unique opportunities and challenges, however, all were committed to applying the Supporting Families LifeCourse Framework to inform solutions they pursued and teams connected with existing initiatives such as promoting integrated employment, addressing waiting lists, or improving access to technology-based supports.

To instigate a shift in culture, CoP teams shared the Supporting Families LifeCourse message at all levels and effectively used it as a platform to “reframe the conversation” across the system. Based on their experiences, the following elements were identified as having a significant impact in fostering change including:

(a) lead with the perspective of people with disabilities and their families; (b) value the role of family; (c) consider all people with IDD and their families; (d) integrate sources of supports; and (e) engage partners and systems beyond the traditional IDD partners.

Lead with the Perspective of People with Disabilities and Their Families – Including individuals with IDD and their families in forming supports is crucial. This inclusive approach honors the experiences of families and people with disabilities and captures their concerns, needs, strengths and ideas. This principle serves as the primary catalyst for change.

CoP participants worked to ensure that families and individuals with IDD had opportunities to share their stories, participate in focus groups and meetings, attend trainings, educate and support other families, and help shape the vision of a good life for all. Successful models of inclusion included provisions to accommodate their participation such as stipends, child care, or convenient community locations.

Value the Role of Family – All people exist within a family, as defined by its members. While this may seem an inherent truth, many factors have disrupted this presumption for people with disabilities and their families. This principle promotes that support strategies encompass the wellbeing and reciprocal roles of all family members across the life cycle, including people with IDD, whether or not members reside in the same household. The role of family represented a significant shift in thinking, particularly related to Medicaid services, which are primarily directed at the person with a disability with few supports aimed at the caregiving family. Operationally, it meant instilling approaches such as supporting family members to have a vision for employment for their loved one with a disability, supporting aging caregivers to prepare for the future, and supporting siblings to maintain a balance between their role as sister or brother, and in some cases caregiver and advocate.

Consider All People with IDD and Their Families – The entire population of people with IDD and their families creates the full picture of what supports are needed across the life span. Considering that the number served through IDD agencies represents a relatively small portion of all those with IDD, it follows that: (a) some number of these individuals may request IDD services in the future; (b) members of this group may be utilizing effective strategies and resources within their communities that keep them from turning to formal services; and (c) that formal systems for support may not offer what individuals and families need.

Teams incorporated this construct to address common issues such as waiting lists, initial contacts with formal systems of support, and bridging connections with community resources. This principle logically pointed to the benefits of working collaboratively across all entities with a vested interest in supporting families, and helped participants identify and form new partnerships and alliances they may not have considered previously.

Integrate Sources of Support – Individuals and families access an array of integrated supports to achieve their vision of a good life, including those funded publicly or privately. This principle encourages people with IDD, their families, and those who support them to first identify the support need, then decide on the most effective source of care to achieve the desired life outcome. The goal is to integrate supports such that individuals with IDD and families are supported to live interdependently as part of their communities.

Including a broad range of supports for people with IDD and their families shifts from complete reliance on formal services offered through the state IDD agency to viewing those services as one option among a larger network of supports available. State-funded resources have a place, and when effectively leveraged can expand and integrate additional supports, potentially increase connections with community and foster interdependence.

Engage partners and systems beyond the traditional IDD partners. – The success of this initiative centered on forming new alliances and working together. Through communication strategies and other efforts, many CoP sites were able to attract new partners. For example, the District of Columbia team formed a partnership with

Georgetown University and a local law firm to address common goals around implementing supported decision-making, a burgeoning approach as an alternative to guardianship. The Oklahoma team collaborated with the state’s largest school district to offer resources based on the Supporting Families LifeCourse Framework to educators. Additionally, the Tennessee team formed working relationships with managed care organizations charged with managing a new waiver to serve individuals with IDD living in their own home or a family member’s home.

Moving from Principles to Practice

CoP participants applied the Supporting Families LifeCourse Framework to modify core aspects of their systems, seeking to transform systems overall to enhance supports to persons with IDD and their families. For example, the new waiver in Tennessee aimed to serve more people and promote employment and community inclusion. Services offered in the waiver, such as Peer-to-Peer Support and Family-to-Family Support, provided a structure to connect people with IDD and families with peers who have had successful experiences with employment. Likewise, in Oklahoma, the CoP team used the principles of the Supporting Families LifeCourse Framework to guide the development of recommendations of a governor’s panel to address the state’s enduring wait list. The District of Columbia introduced concepts and tools related to the Supporting Families LifeCourse Framework as part of the District's "No Wrong Door" initiative for application universally across departments and populations with long-term support needs.

Moving Forward

The CoP structure provided a platform for collaborative learning to occur with an array of stakeholders at all levels. Creating space for innovation to occur among stakeholders led to validation of existing and creation of new policies and practices that support the role of families in the lives of persons with IDD.

The Supporting Families LifeCourse Framework provided a "common language" uniting stakeholders representing many disciplines and ages across the lifespan. The simplicity and versatility of the framework allows for use as organizing and implementation strategies and stimulates quick adoption and rapid scaling within and beyond the CoP members.

The challenge moving forward is capitalization on the momentum that CoP and the Supporting Families LifeCourse Framework has initiated across the country as well as capturing specific impacts. This requires deeper exploration of the outcomes of the practices and policies implemented at the state, organizational, professional, family and individual level. Potential next steps include: (a) building on promising practices that can be implemented with fidelity across the country, and (b) developing specific demonstrations related to the Supporting Families LifeCourse tools.

The shift that was cultivated through the National Community of Practice for Supporting Families of Individuals with Intellectual and Developmental Disabilities will undoubtedly be recognized as a pivotal moment in the field of intellectual and developmental disabilities. The success of this initiative centered on forming new alliances and working together. It was through the collective effort of all involved that a new trajectory for supporting individuals with IDD and their families was plotted.

About the Authors

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