



ISSUE BRIEF

LifeCourse in Action: Reaching "the All" in Tennessee, March 2016


All people have the right to live, love, work, play and pursue their life aspirations in their communities.

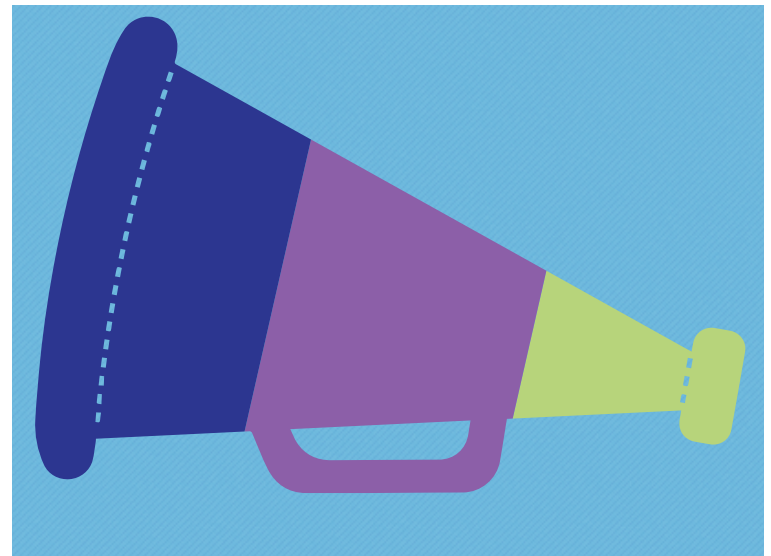
The Community of Practice for Supporting Families of Individuals with Intellectual and Developmental Disabilities (I/DD) holds the core belief that all people have the right to live, love, work, play and pursue their life aspirations in their communities. Across the country, our culture is embracing this belief. It is necessary to change not only our conversations, but the way we think about people with I/DD and their families and the supports they need to live a good life.

The Community of Practice (CoP) is working to discover integrated, flexible, and innovative strategies for supporting the entire family, rather than solely focusing on formal services. As a result, a universal strategy for providing supports based on thinking that emerged from the public health field was developed. Read on to learn more about this strategy and how the messages of the LifeCourse framework and tools are being spread across the state of Tennessee by members of the CoP state team to enhance supports to families.

This issue brief focuses on how the LifeCourse framework is:

- reaching everyday families through generic community and technology resources,
- being carried to the front lines through public-private partnerships, and
- changing how services to individuals with I/DD and their families are provided in Tennessee.

Read on to see real life examples of how the LifeCourse message is being delivered to a variety of audiences in the state of Tennessee. 



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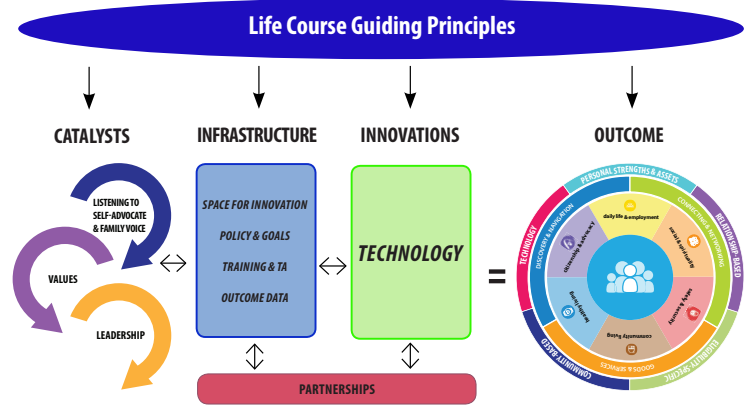
THE LIFECOURSE FRAMEWORK RESOURCES



INNOVATIONS IN SUPPORTING FAMILIES
COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS SERIES

THE NATIONAL COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS CHANGE

The CoP uses a framework for systems change adapted from the State Employment Leadership Network (SELN) (see right). The outcome of systems change is supports that help individuals and families achieve a good quality of life. Systems change is driven by innovations in supports offered to families, changes in infrastructure that make it more effective and flexible, and partnerships with organizations and the community. Family and self-advocate voices, values, and leadership are the catalysts that add fuel to the fire and make systems change more personal. Finally, all of this change is happening under the umbrella of the LifeCourse framework (see page 7), which promotes the idea that all people have the right to live, love, work, play and pursue their life aspirations in the community. Learn more about the framework for systems change at supportstofamilies.org.



Michelle "Shell" Reynolds, PhD. UMKC Institute for Human Development, UCEDD. Revised June 2014. Adapted from Hall et al, 2007

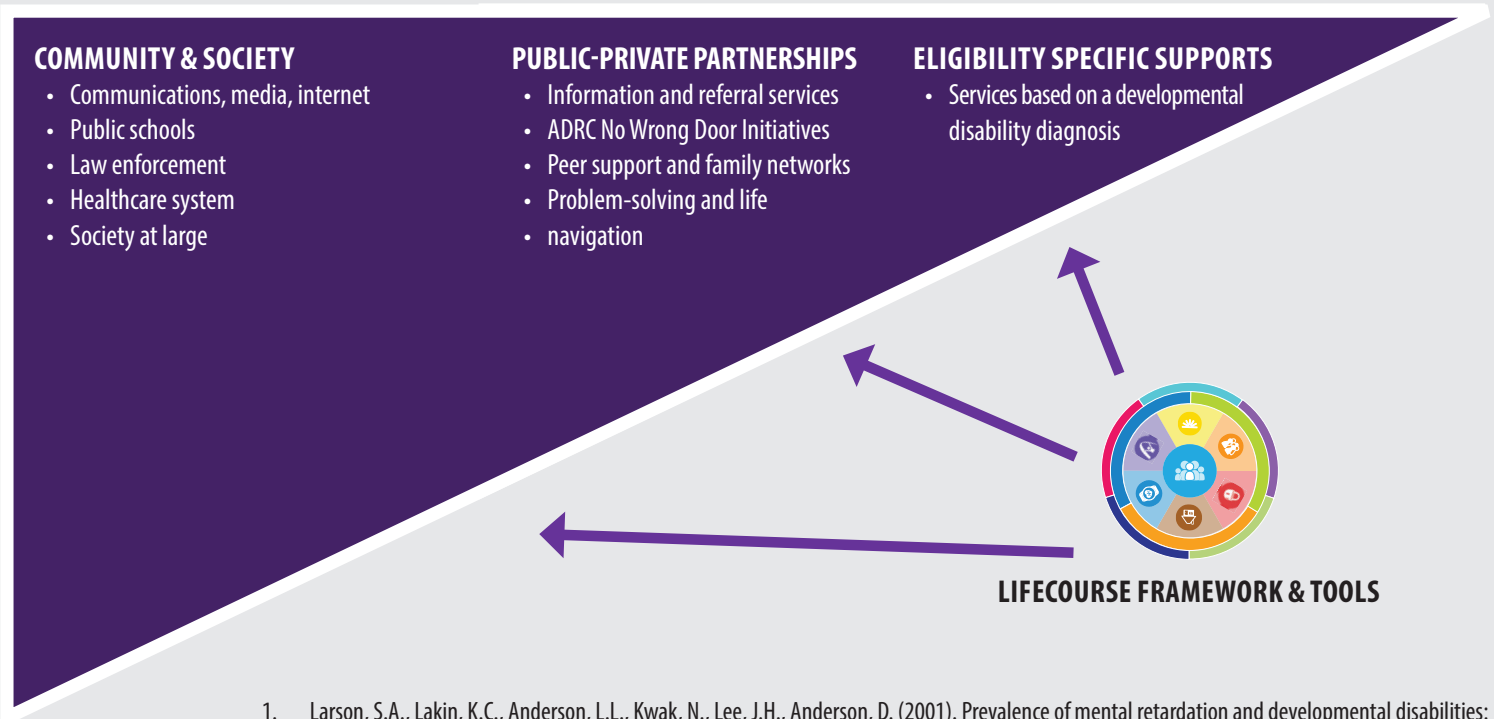
UNIVERSAL STRATEGY FOR PROVIDING SUPPORTS: USING THE LIFECOURSE TO SUPPORT FAMILIES

The CoP has developed a universal strategy for providing supports based on thinking that emerged from the public health field (see below). The left region of the triangle lists 'interventions' that can be implemented on a community-wide scale to improve access for all people. The middle region shows policies and practices frequently used in the partnerships between public and private entities. Finally, the right region portrays paid, formal service systems.

Currently, only 25% of people with I/DD access paid supports from the DD service system.¹ Federal and state budgets do not allow systems to serve all people with disabilities, so innovative strategies which acknowledge the changing paradigm calling for real jobs, relationships, and lives in the community are needed.

The LifeCourse Framework was developed by families FOR individuals and families to help guide them while thinking about the future and trouble-shooting every day life. The LifeCourse Framework originally began as a set of tools and educational materials; however, it has since grown to foster professional development, support job functions of human service professionals, facilitate organizational and cultural change, and enhance systems of supports to families.

Read on to find out how the LifeCourse framework and tools are helping individuals and families in their everyday lives, while at the same time changing entire systems to enhance supports to all families. ☺



COMMUNITY & SOCIETY: TENNESSEE DEVELOPMENTAL DISABILITIES COUNCIL

The concept of the 'All' has helped CoP state teams, including the Tennessee (TN) team, expand their thinking about how to reach and support all families, and the Universal Strategy has put new organizations and potential partnerships on their radar. This new way of thinking prompted the TN DD Council to connect with their state University Extension, which has had significant results in terms of spreading the message of supporting families and the LifeCourse.

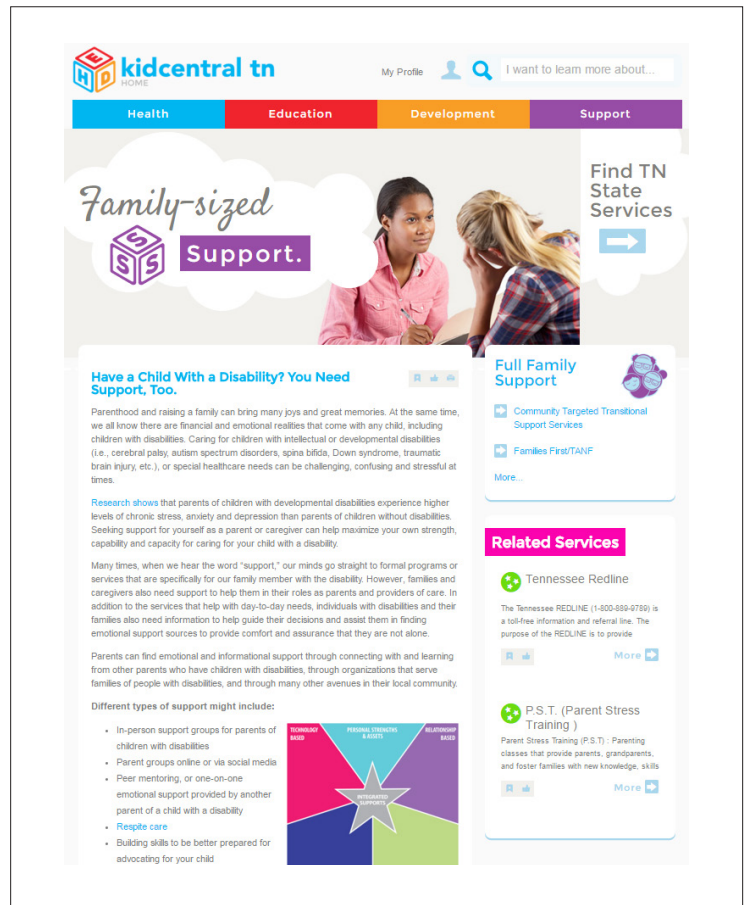
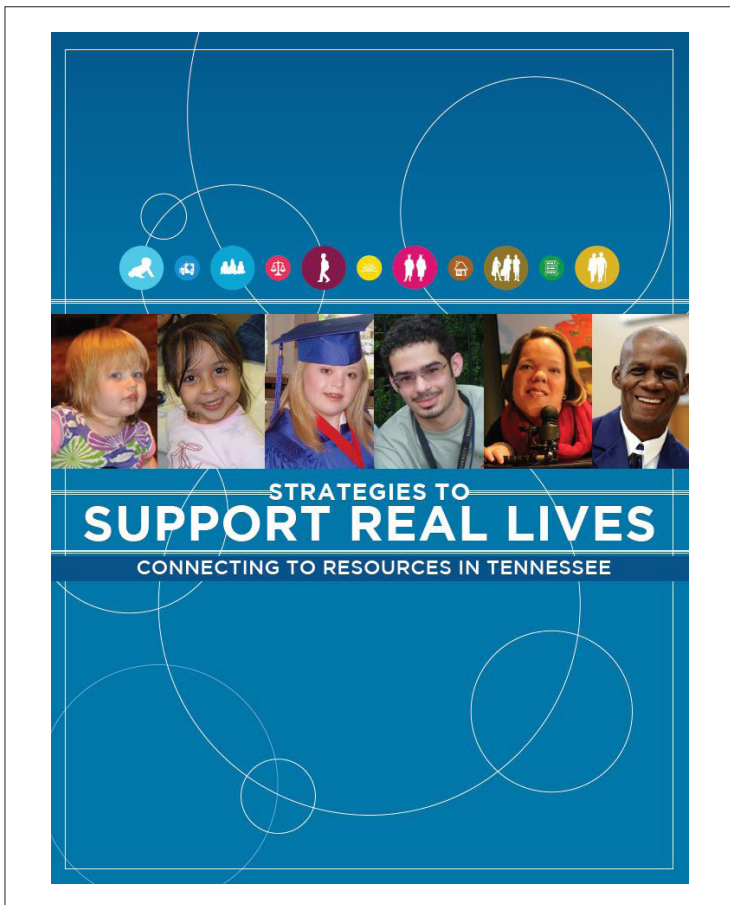
In 2014, when the University of Tennessee (UT) Extension was preparing to host a policy seminar about family-friendly public policy, the TN DD Council asked to contribute to the section on disability and families to the policy brief being disseminated to legislators. That initial contact has led to a connection with a statewide network that reaches individuals and families from each corner of Tennessee. That same year, the Council developed a LifeCourse folder (pictured below, left) for their state to enhance their efforts to connect families with information and support. The folder has been an instrumental tool in nurturing the budding relationship with the Extension. First, they sent out an introduction letter with the folder to spark interest in the new resource. A few months later, they distributed larger batches with targeted information about services and supports for families based on location.

The dissemination partnership has enhanced the work of both the Council and the UT Extension. Sharing their specialized knowledge informs the work

of both organizations. They are also increasing the effectiveness of their initiatives by collaborating to expand the reach of their shared values of improving lives and building community. The DD Council has been invited to present during regional professional development sessions required for Extension agents in every county, which exposed the agents to new understanding about disability. UT Extension has provided training at the Council's Partners in Policymaking Reunion to increase awareness of family leaders and self-advocates in Tennessee of the Extension's initiatives.

While conducting outreach to community organizations in middle Tennessee through Lunch 'n Learns, conferences, and other events, the DD Council established a number of new partnerships with organizations that work with families from all walks of life. One was a new content collaboration with KidCentralTN.com (pictured below, right), an online 'one-stop shop' for information for ALL Tennessee families hosted by the Governor's Children's Cabinet. After attending one of the Lunch 'n Learns, the Cabinet has been partnering with the DD Council to expand content relevant to families of individuals with disabilities and push information about supporting families and the LifeCourse out to the mainstream through social media.

To hear even more about what the TN DD Council is doing to reach "the All," watch the archived presentation at supportstofamilies.org ©



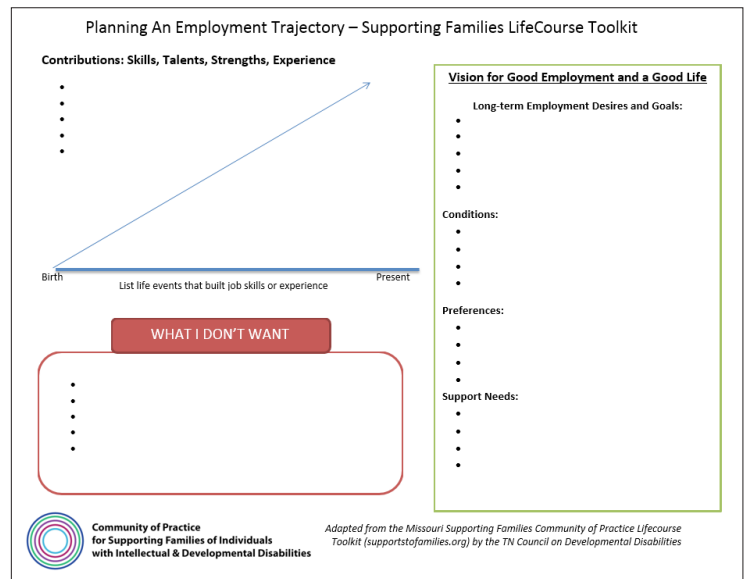
PUBLIC-PRIVATE PARTNERSHIPS: THE ARC TENNESSEE

The Arc Tennessee (TN) has been a vital part of the Tennessee Supporting Families Community of Practice since it began in 2013. The Arc TN works with many who are part of the population not receiving formal services, which is closer to 85 percent in their state. As a result, the organization is always looking for tools to help these individuals and families. Staff from The Arc TN have expressed that the LifeCourse materials and resources shared by the TN CoP team have provided tools to assist their advocates and staff in helping families create a vision and develop action plans for supporting a loved one with a disability. The Arc TN invited the Council on Developmental Disabilities to share the LifeCourse with family coalitions in Memphis, Nashville and Chattanooga to increase awareness of the framework and tools and their use in planning for employment (pictured, right).

In 2015, The Arc TN applied for and received a grant from The Arc US to host a one-day summit on how families caring for loved ones who have disabilities as well as those who are aging can be better supported in their state. The Arc TN saw this as an opportunity to build upon the goals of the Community of Practice and enhancing supports to even more families by including the aging population. The summit brought together over 60 attendees representing individuals with disabilities and their family members, community based organizations, government agencies, university faculty and other stakeholders to develop a strategic plan aimed at help to enhance supports to families in Tennessee.

The overall goal of the plan is to improve supports to all families of people with disabilities and seniors in the state. The Arc TN's long range goals of the grant are to continue collaborating with other organizations focused on supporting families in caregiver roles of people with disabilities or who are elderly and maximize the use of the LifeCourse tools and framework being shared through the Community of Practice. Objectives of the project include continuing to identify challenges and available resources to support families within both formal and informal systems as well as improving coordination and information sharing to promote supports to families.

To hear The Arc TN staff explain how they are serving as a bridge between the general public and family-serving organizations, watch the archived presentation at supportstofamilies.org ©



Watch the archived *Innovations* webinar, **LifeCourse In Action: Reaching the All in Tennessee**, to hear in depth how the LifeCourse is being rolled out at all levels across the Community of Practice state.



ELIGIBILITY-SPECIFIC SUPPORTS: TENNCARE

From the TN Supporting Families E-Newsletter, Issue 18. <http://eepurl.com/bCiKU1>

Tennessee will become the first state in the United States to develop and implement an integrated, Home and Community-Based Services waiver program that aligns incentives toward promoting and supporting integrated, competitive employment and independent living as the first and preferred option for all individuals with intellectual and developmental disabilities. The new waiver program is called "Employment and Community First CHOICES" for Tennesseans with intellectual and developmental disabilities. This new program is set to start enrolling eligible individuals beginning July 1, 2016.

The TN Department of Intellectual and Developmental Disabilities (DIDD) and the TN DD Council have partnered closely with TennCare during the development of the ECF CHOICES program. They spent time meeting with individuals with disabilities, families, and advocates, collecting their input on what they wanted and needed from disability services. While integrated employment opportunities for competitive wages and community living options emerged as priorities, families also said they wanted assistance in navigating service systems, knowledge about building community relationships and engagement, and support from other families who have experienced similar situations.

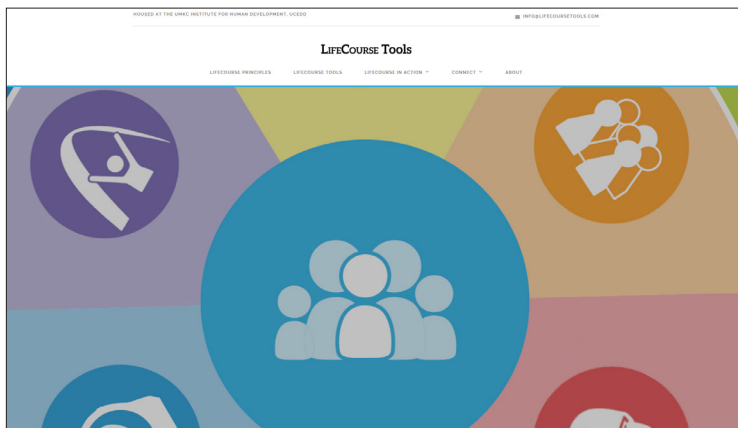
As a result of this feedback, many services and supports that previously weren't offered will be available to eligible individuals and families through the new waiver. Some of these options include:

- Family Caregiver Education and Training: "This service provides reimbursement up to \$500 per year to offset the costs of educational materials, training programs, workshops and conferences to provide education and support to family caregivers in order to preserve the family unit and increase confidence, stamina and empowerment."
- Community Support Development, Organization and Navigation: "These services help individuals and family caregivers to develop a network for information and mutual support from others who receive services or family caregivers of individuals with disabilities."



- It assists individuals with disabilities and family caregivers with identifying and utilizing supports available from community-serving organizations and businesses, such as churches, schools, colleges, businesses, libraries, neighborhood associations, clubs, recreational entities and other community-serving organizations."
- Peer-to-Peer Self-Direction, Employment and Community Support and Navigation: "These services assist an individual and their family members in understanding and considering self-direction, integrated employment and independent community living options, and addressing questions and concerns related to such options through the experiences of a peer who has successfully self-directed his or her own services and/or achieved integrated employment and community living goals."

To hear details about the new waiver and how TennCare is expanding services and supports to individuals and families based on their needs, watch the archived presentation at supportstofamilies.org ©



Log on to lifecoursetools.com to view examples of how the LifeCourse framework and tools are helping organizations and systems conduct outreach, provide information, organize supports and programming, guide decision-making and policies, and facilitate strategic thinking and planning!





VISIT US ONLINE

to view all *Innovations* series materials, including archived webinars and previous issue briefs!

Overview of the LifeCourse Framework
March 2015

Focusing on the Front Door
April 2015

We're All in This Together: Uniting the
Movements for a Good Life, July 2015

ISSUE BRIEF Overview of the LifeCourse Framework
March 2015 (Updated November 2015)

All people have the right to live, love, work, play and pursue their life aspirations in their communities.

In not-so-recent history, the common practice of professionals in the medical field when a person with a disability was born was to suggest to their family they be institutionalized. People with disabilities were sent to live in institutions, separating entire generations from their families and the communities in which they were born, because people were afraid of the stigma of disability.

Today individuals with IDD and their families embrace the idea that people with disabilities have skills, dreams, and feelings like everyone else and belong with their families. As principles of integration and inclusion are realized, a new generation of youth with disabilities are growing up in classrooms with their peers, going to college, getting married, and raising families of their own.

Embracing this shift in paradigm means thinking differently about what it means to support individuals with disabilities and their families. Our field is constantly growing and changing as we have been working hard for many years to steer our system away from an institutional focus to become a more person-centered system.

Thinking differently about supporting families means recognizing that people exist and have reciprocal roles within a family system, which adjust as the individual members change and age. The entire family, each of the individual members collectively but also the whole unit, needs support to ensure all of the members are able to successfully live a good life in the community.

THE LIFECOURSE FRAMEWORK

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- Constructing a Shared Storyline
- Applying the Trajectory to Policy, Practice and Planning
- Building Family & Self-Advocate Networks
- Integrating Supports at All Levels
- Partnering to Disseminate a Consistent Message

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COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS SERIES

ISSUE BRIEF Front Door to Long-Term Services and Supports, April 2015

All people have the right to live, love, work, play and pursue their life aspirations in their communities.

The Community of Practice for Supporting Families of Individuals with Intellectual and Developmental Disabilities (IDD) holds the core belief that all people have the right to live, love, work, play and pursue their life aspirations in their communities. Making this right a reality for all people means we must reframe our thinking about people with intellectual and developmental disabilities and their families and the supports they need to live a good life.

The Community of Practice (CoP) is working on discovering innovative strategies for supporting the entire family that are flexible and integrated, instead of focusing solely on formal services. This issue brief focuses on how states can look at the Front Door of long-term services and supports.

The Front Door of long-term services and supports is defined as the first interaction involving the family reaching out to the professional world for support. Many times, the family is encouraged to engage with the service system but is unsure of what services may be available or what to request. The traditional response of professionals in the service system has been to provide families with information about services and set them on the trajectory to solely engaging in formal services.

Changing that very first interaction at the front door to better provide information and hope for the future, opportunities to connect with other families and networks, and think of options outside of the formal system for supporting people to achieve the good life is the focus of this issue brief. Read on to discover how two states have worked to make this initial encounter at the front door more functional and family-friendly and what they learned in the process.

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FOCUSING ON MISSOURI

INFRASTRUCTURE: REFRAMING THE FRONT DOOR

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ISSUE BRIEF We're All in This Together: Uniting the Movements for a Good Life, July 2015

All people have the right to live, love, work, play and pursue their life aspirations in their communities.

The Community of Practice for Supporting Families of Individuals with Intellectual and Developmental Disabilities (IDD) holds the core belief that all people have the right to live, love, work, play and pursue their life aspirations in their communities. Making this right a reality for all people means we must reframe our thinking about people with intellectual and developmental disabilities and their families and the supports they need to live a good life.

The Community of Practice (CoP) is working on discovering innovative strategies for supporting the entire family, which are flexible and integrated, instead of focusing solely on formal services. This issue brief focuses on uniting the parent, self-advocate, and sibling movements to support the entire family.

The self-advocate, parent, and sibling movements have been working separately for many years to improve the quality of life of individuals with IDD. Recently, these three movements have begun to converge to form a unique force called the "triad approach." They are working together across the United States and in the Community of Practice states to try new strategies for connecting families on the frontlines, improving policies and practices for families, and serving as a voice for individuals with disabilities and their families.

Working together to create better lives is at the core of the Community of Practice. In this issue brief, you will hear from Parent USA, the Sibling Learning Network, and Self-Advocates Becoming Empowered as they come together to better support individuals with disabilities and their families through peer support and informing systems at the state and national level.

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THE NATIONAL COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS CHANGE

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PARTNERING TO LEAD THE CHANGE

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ISSUE BRIEF Reframing the Conversation at All Levels, September 2015

All people have the right to live, love, work, play and pursue their life aspirations in their communities.

The Community of Practice for Supporting Families of Individuals with Intellectual and Developmental Disabilities (IDD) holds the core belief that all people have the right to live, love, work, play and pursue their life aspirations in their communities. Across the country, our culture is embracing this belief. It is necessary to change not only our conversations, but the way we think about people with IDD and their families and the supports they need to live a good life.

The Community of Practice (CoP) is working on discovering integrated, flexible, and innovative strategies for supporting the entire family, rather than focusing solely on formal services. This issue brief focuses on "reframing," or thinking and talking about things in a new way. Reframing is a part of making transformational change, which leads to the:

- Fundamental reordering of thinking, beliefs, culture, relationships, and behavior;
- turning assumptions inside out and disrupting familiar rituals and structures; and
- redefining command and control relationships in favor of co-creative partnerships.¹

Read on to see how three states have started changing the way they think and talk about supporting individuals with IDD and their families at all levels. We will look at resources and materials they have developed and disseminated to individuals and their families, professionals and organizations in the community, as well as state systems and policymakers.

1. Melrose, R. (2013). *Creating Blue Space: Fostering Innovative Support Practices for People with Developmental Disabilities*. (p. 75). Toronto, Ontario: Inclusion Press.

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THE NATIONAL COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS CHANGE

REFRAMING THE CONVERSATION AT ALL LEVELS: FOCUSING ON REFRAMING STRATEGIES

THE LIFECOURSE FRAMEWORK

REFRAMING IN OKLAHOMA

REFRAMING IN TENNESSEE

REFRAMING IN WASHINGTON STATE

REFRAMING IN MISSOURI, CONNECTICUT, AND DC

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ISSUE BRIEF Technology & Supporting Families, November 2015

All people have the right to live, love, work, play and pursue their life aspirations in their communities.

The Community of Practice for Supporting Families of Individuals with Intellectual and Developmental Disabilities (IDD) holds the core belief that all people have the right to live, love, work, play and pursue their life aspirations in their communities. Across the country, our culture is embracing this belief. It is necessary to change not only our conversations, but the way we think about people with IDD and their families and the supports they need to live a good life.

The Community of Practice (CoP) is working on discovering integrated, flexible, and innovative strategies for supporting the entire family, rather than focusing solely on formal services. As we move forward as a society that becomes increasingly dependent on technology to function, thinking differently about supporting families means asking how we can use both technology designed specifically to help people with disabilities, as well as everyday technology that is used by everybody.

This issue brief focuses on:

- how technology can be used as a support to achieve the good life;
- real stories of how individuals with disabilities and their caregivers found technology solutions to meet their needs;
- resources available to help individuals, families, and the professionals who support them, to connect with the technology that make sense for them.

Read on to find out how families are making technology work for them to enhance independent living or support caregiving.

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THE NATIONAL COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS CHANGE

UNIVERSAL STRATEGIES FOR PROVIDING SUPPORTS:

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TECHNOLOGY AND SUPPORTING FAMILIES

TIM, AARON, SANDRA AND BEN

SUPPORT AND FUNDING FOR TECHNOLOGY

TECHNOLOGY IN THE COMMUNITY OF PRACTICE STATES

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ISSUE BRIEF LifeCourse in Action: Implementation at All Levels in Missouri, January 2016

All people have the right to live, love, work, play and pursue their life aspirations in their communities.

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The Community of Practice (CoP) is working on discovering integrated, flexible, and innovative strategies for supporting the entire family, rather than focusing solely on formal services.

This issue brief focuses on how the LifeCourse Framework is being used:

- at the individual and family level to help them troubleshoot issues that arise as well as create and articulate a vision for the future;
- at the professional level to build human service professionals' capacity to educate and inform families as well as help them plan and access supports;
- at the organizational level to provide an organizing framework for programming and activities;
- at the community level to facilitate transformational change and bring together stakeholders; and
- at the systems level to influence the implementation and compliance with new CMS Home and Community Based Services rules and person-centered guidelines.

Read on to see real life examples of how the LifeCourse is being implemented at all levels in the state of Missouri.

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FOCUSING ON SUPPORT COORDINATORS

MAKING SWEEPING CHANGES

CREATING TRANSFORMATIONAL CHANGE

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supportstofamilies.org/resources/

The LifeCourse Framework

REFRAMING OUR THINKING TO ENHANCE SUPPORTS TO FAMILIES

The LifeCourse framework was developed by families to help individuals with disabilities and families at any age or stage of life develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live. Individuals and families may focus on their current situation and stage of life or may find it helpful to look ahead to start thinking about what they can do or learn now that will help build an inclusive productive life in the future. It was developed with individuals with developmental or intellectual disabilities and their families in mind. The framework is designed to help any person with a disability think about their life, not just individuals known by the service system. Although the framework was developed for people with disabilities, it is designed universally, and could be used by any family making a life plan, whether they have a member with a disability or not.

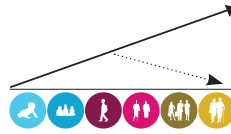
LIFECOURSE FRAMEWORK/PRINCIPLES

ALL INDIVIDUALS AND FAMILIES



ALL individuals and families, whether they are known to the DD system and/or receive formal services or not, are considered in our vision, values, policies and practices for supporting people with intellectual and developmental disabilities.

LIFE STAGES AND 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.

FAMILY SYSTEM 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 roles and needs of all family members change as they age through the family cycles.

INDIVIDUAL AND FAMILY SUPPORTS



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.

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 anyone, relationship based supports, technology, and that take into account the assets and strengths of the individual and family.

LIFE DOMAINS



People lead whole lives made up of specific and 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.

POLICY AND 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.



RESOURCES

INNOVATIONS IN SUPPORTING FAMILIES

COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS CHANGE WEBINAR SERIES

The *Innovations in Supporting Families* is a FREE webinar series focused on innovative strategies to enhance the systems that support families of individuals with intellectual & developmental disabilities. The series includes presentations from national experts about innovative strategies related to the experience of individuals and families as they navigate through their life course and use supports to assist them.

This webinar series is for stakeholders interested in enhancing the systems and policies that impact individuals with intellectual and developmental disabilities and their families, including:

- self-advocate and family leaders,
- leaders of community organizations and disability services, and
- state and federal policymakers.

Webinars are hosted live every other month beginning January 2015 and archived for later viewing at nasddd.org and supportstofamilies.org.

Learn more about the series at supportstofamilies.org

The screenshot shows the homepage of the Supporting Families website. At the top, there is a navigation bar with links for Connecticut, District of Columbia (DC), Missouri, Oklahoma, Tennessee, and Washington. Below this is the main header with the logo and the text "SUPPORTING FAMILIES of individuals with intellectual & developmental disabilities". A secondary navigation bar includes links for About, The States, Resources, News & Events, and Contact. The main content area features a "LATEST NEWS" section with a featured article titled "LifeCourse Tools in Action: Reaching the All in Tennessee CoP - Innovations Webinar March 24, 2016". To the right, there is a "FUNDED by" section listing the Administration on Intellectual and Developmental Disabilities, and a "NATIONAL PARTNERS" section listing various organizations like NASDDDS, UMKC, HSR, ASAN, AUUC, and NACDD. At the bottom right, there is a "MAILING LIST" sign-up form with fields for "First Name" and "Last Name".

VISIT THE
COMMUNITY OF PRACTICE
ONLINE AT
supportstofamilies.org
to get the latest updates
about what we're learning
about supporting families
in your email inbox.

Project Leadership



This project is funded by the Administration on Intellectual & Developmental Disabilities, grant number ACF 90DN0298. AIDD is dedicated to ensuring that individuals with developmental disabilities and their families are able to fully participate in and contribute to all aspects of community life in the United States and its territories.