

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 (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 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 part of making transformational change, which calls for the:

- fundamental reordering of thinking, beliefs, culture, relationships, and behavior,
- turning assumptions inside out and disrupting familiar rituals and structures, and
- rejecting 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 I/DD 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. Meissner, H. (2013). *Creating Blue Space: Fostering Innovative Support Practices for People with Developmental Disabilities*. (p. 75). Toronto, Ontario: Inclusion Press.



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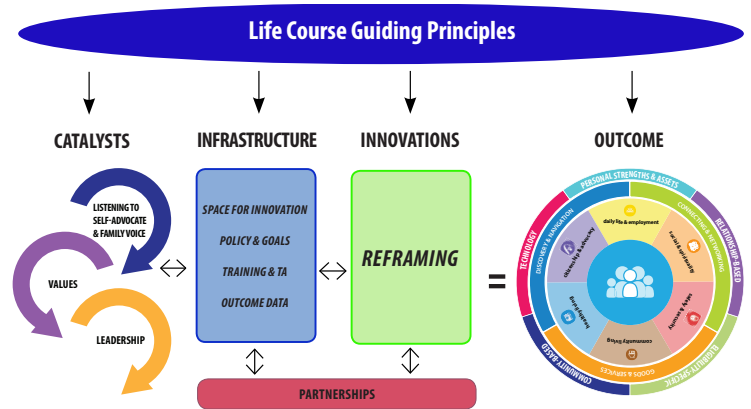
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THE NATIONAL COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS CHANGE

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

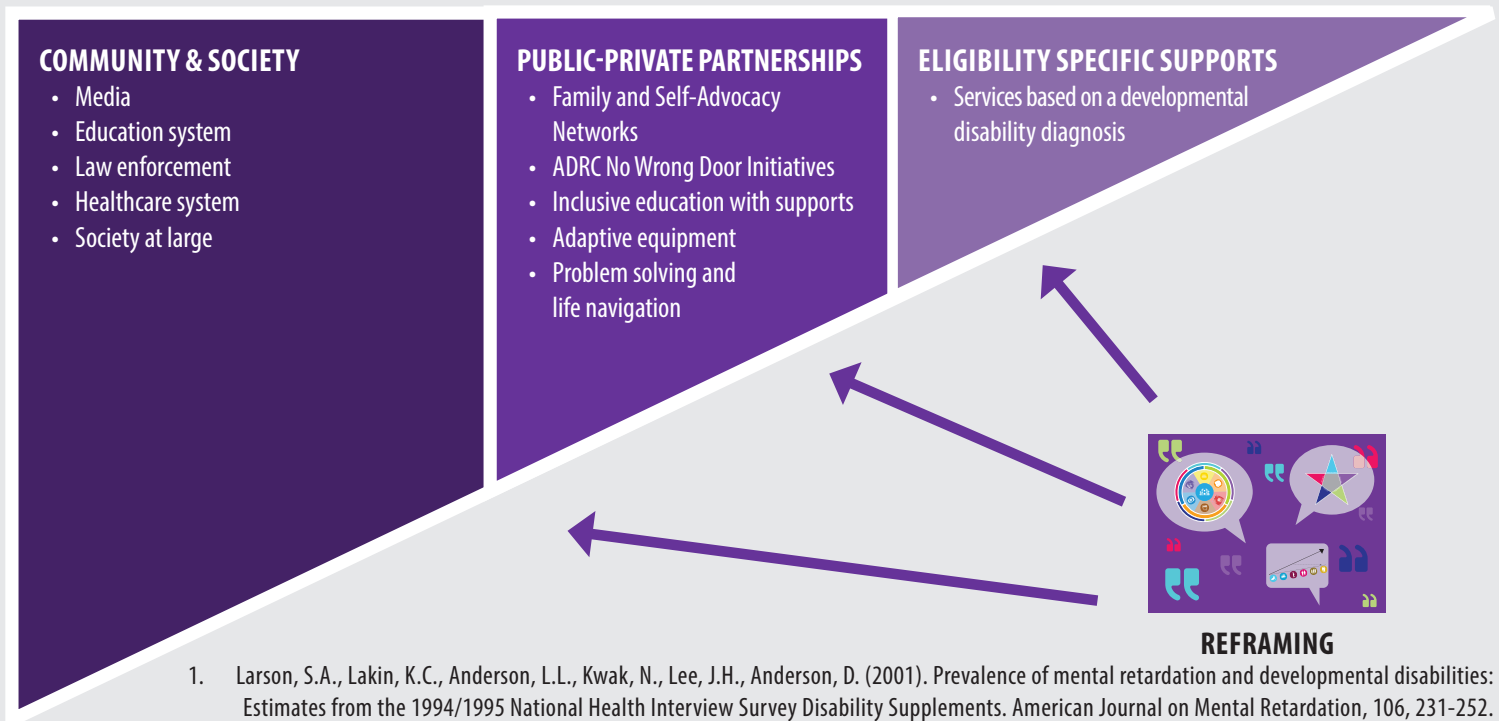
REFRAMING THE CONVERSATION AT ALL LEVELS: FOCUSING REFRAMING STRATEGIES

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 describes 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 receive paid supports from the DD service system¹. 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, real relationships, and real lives in the community are needed.

"At every level of organization from the individual to the larger society, people continuously attempt to cope and adapt to specific life circumstances within a prevailing worldview."² Reframing has the potential to transform not only formal systems of supports, but also those partnerships between organizations that reach individuals and their families as well as within society at large. Part of an integrated strategy for transformational change, reframing has great potential to reach many, from everyday citizens, to large government systems.



1. Larson, S.A., Lakin, K.C., Anderson, L.L., Kwak, N., Lee, J.H., Anderson, D. (2001). Prevalence of mental retardation and developmental disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements. *American Journal on Mental Retardation*, 106, 231-252.
 2. Meissner, H. (2013). *Creating Blue Space: Fostering Innovative Support Practices for People with Developmental Disabilities*. (p.48). Toronto, Ontario: Inclusion Press.

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.

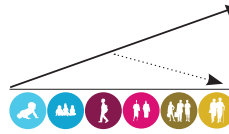
LIFECOURSE FRAMEWORK/PRINCIPLES

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.



REFRAMING IN OKLAHOMA

The idea of a good life and the principles of the LifeCourse framework have been fermenting in the thinking and everyday practices of the Oklahoma (OK) CoP team since they embarked on their journey to enhance supports to families in their state. Ann Trudgeon, OK Developmental Disabilities Council director, reported that the team's reframing efforts have been steadily building over time: "We took the opportunity to really learn the tools and philosophy before deciding on a course of action."

First, the OK team put together a video of self-advocates from across the state sharing what their good life looked like. From there, the message of a Good Life spread across the state. In addition to the video, outputs of the reframing efforts include a Good Life resource folder, a LifeCourse Experiences and Questions booklet, as well as two brochures, one to help families understand one of the waivers offered in their state and another rights and responsibilities of people receiving services.

The OK Developmental Disabilities Council incorporated the goal of a Good Life for individuals with disabilities into their new state plan goals. It also reorganized the Youth Leadership Forum, using the Good Life message and the LifeCourse framework to help them organize their programming. Finally, the OK Partners in Policymaking revised their curriculum using the LifeCourse.

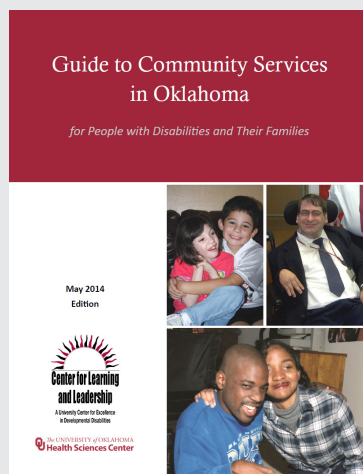
In addition to products developed and programmatic changes implemented by the members of the state CoP team, the idea of a Good Life has reached many different audiences through the team's work with their partners. The Good Life was woven into the theme for the annual governor's conference, annual Joining Forces conference for families and caregivers, as well as the 2015 developmental disabilities awareness day. Across the state, individuals, families, organizations, and policymakers are all becoming vested in promoting the belief that all individuals have the right to a good life. 🌀

BRANDING THE GOOD LIFE



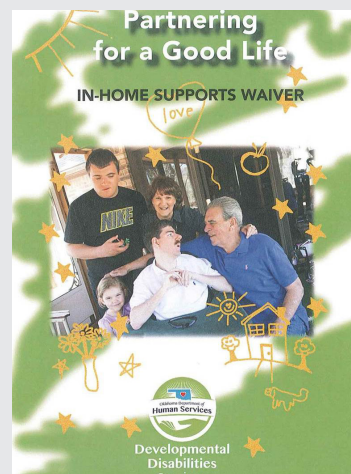
GOOD LIFE FOLDER

The OK Good Life folder lists organizations and projects that support individuals with disabilities and their families, organized by life domain. The Good Life resource folder was purposely designed as a companion to the Guide to Community Services, which features eligibility-specific resources that individuals and families may access. It was meant to serve as a reminder that generic community supports (listed on the folder) should wrap around formal services.



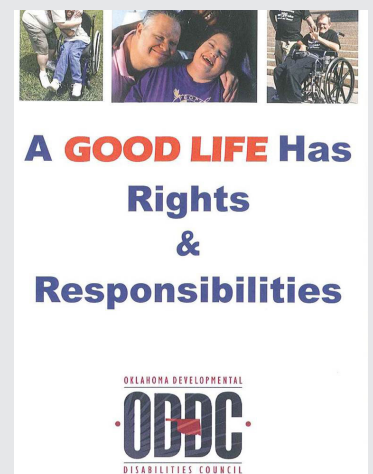
GUIDE TO COMMUNITY SERVICES

The *Guide to Community Services in Oklahoma* was developed in 2014 to help individuals and families navigate formal supports in Oklahoma. The Guide includes information on how families can sign up for medical coverage, apply for waivers, receive assistance with basic needs, and connect with disability services.



WAIVER BROCHURE

The OK Department of Human Services, Developmental Disabilities Services created this guide, branded with the Good Life, to explain the In-Home Supports Medicaid waiver offered in their state.



RIGHTS & RESPONSIBILITIES GUIDE


Advocates have long had a "push-pull" relationship about rights vs. responsibilities. The Oklahoma DD Council wanted to find a way to assert the necessary balance between the two, so it created this short, casual guide. It has been tremendously well-received and thousands have been disseminated. The brochure was developed for self-advocacy organizations, provider organizations, advocacy organizations, and several state agencies, including Human Services, Education, and Rehabilitation Services.



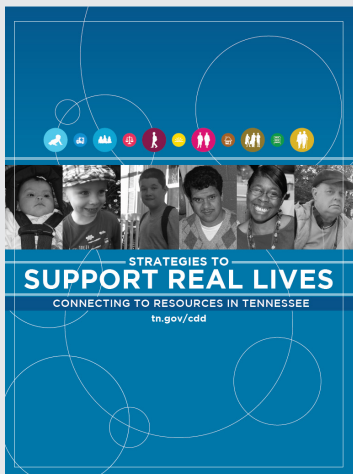
REFRAMING IN TENNESSEE

Tennessee's (TN) team is working strategically to expand the reach of their messaging to all individuals and families, focusing on not only disseminating information to families, but also developing ways to open the channels of communications to learn from families. The team has identified families and individuals with disabilities as their primary audience. Their secondary audience is professionals in the disability field and state agency partners. The key messages they want to share are the value of accessing quality information and connecting and networking with other families as well as using integrated supports to make real lives happen.

In Spring of 2014, the TN Developmental Disabilities Council launched a Supporting Families monthly newsletter. In just over a year, the mailing list has increased by over 250 subscribers. Topics have covered planning for employment, integrating supports, involving individuals and families in policy and planning, and connecting families through peer-to-peer support.

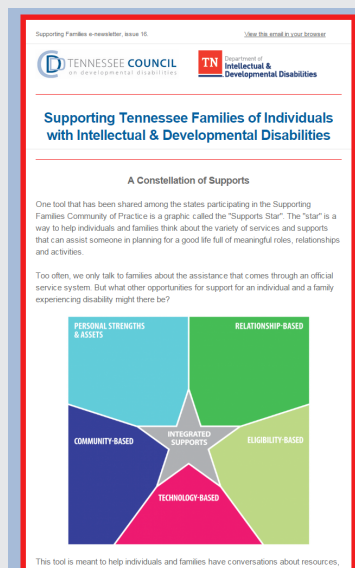
Another example of reframing in Tennessee is the Kindred Stories Project. The Kindred Stories project aims to give individuals with disabilities and their friends and families a forum to share their voices and stories, while educating policymakers about the experiences of constituents with disabilities in their districts. The TN team partnered with Vanderbilt, the University Center for Excellence in Developmental Disabilities in their state, on the Kindred Stories Project. They worked with students, who interviewed 15 families from all walks of life about their use of and access to formal systems of support and informal community supports with the ultimate goal of compiling a special collection on Supporting Families to print and share online. The collection's purpose is two-fold: 1) to include "recommendations for families" to use as practical tool showing successes and challenges as well as educate families how others are "making it work" with formal and/or informal supports and 2) to inform policymakers about families' needs. The collection will be released in 2016. 

SUPPORTING FAMILIES ACROSS THE LIFECOURSE



REAL LIVES FOLDER

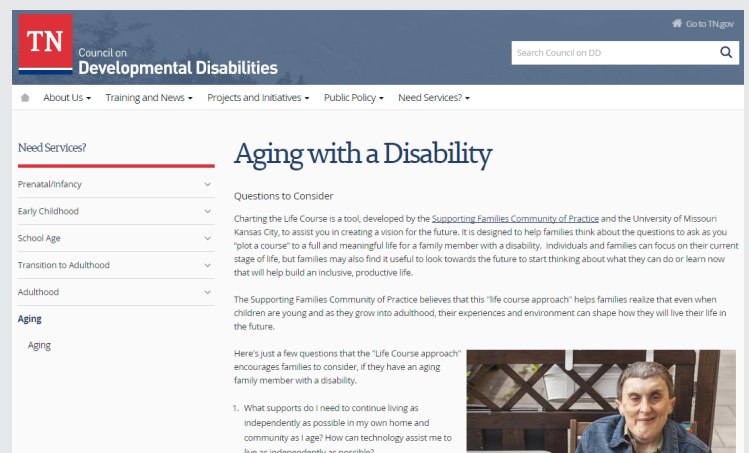
In Spring of 2014, Tennessee developed a resource folder to disseminate to individuals and their families, as well as stakeholders across the state. The development of the folder led to new relationships with community partners, including the University extension offices. This new partnership helped expand the reach of the supporting families message across the state.



SUPPORTING FAMILIES E-NEWS

Topics have included planning for employment, integrating supports, involving individuals and families in policy and planning, connecting families through peer-to-peer support and more. You can subscribe at <http://eepurl.com/BDhSH>

TENNESSEE COUNCIL ON DEVELOPMENTAL DISABILITIES WEBSITE



The TN DD Council has developed a section of their website based on the LifeCourse life stages, that introduces visitors to the LifeCourse approach and presents just a few questions from the Charting the LifeCourse: Experiences and Questions booklet. To check it out, visit www.tn.gov/cdd



REFRAMING IN WASHINGTON

Reframing efforts in Washington (WA) state have been brewing for quite some time now. The focus of their efforts is helping people understand that life is about more than just services-- but relationships, communities, and technologies-- that can help support them to have real lives.

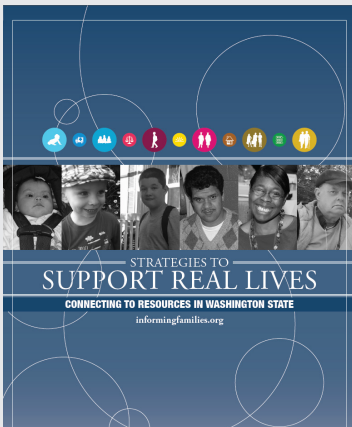
The WA Developmental Disabilities Council has been working to keep people informed through Informing Families. Informing Families (informingfamilies.org) is a resource provided by the WA State Developmental Disabilities Council, in collaboration with the Developmental Disabilities Administration and other partners throughout the state. The website, which has long provided information to individuals

and families, was recently completely overhauled by the Council, centering it around the life stages in the LifeCourse framework. The website (pictured below, right) continues to offer trusted news and information to individuals and families that empowers them to be active participants in planning and building a network of support and opportunities.

In addition to the Informing Families initiative, the WA CoP team has developed a virtual person-centered planning tool, hosted conversations with siblings focused on planning for a good life, and participated in family-focused events to reinforce the idea of living a real life. 🌐

SUPPORTING REAL LIVES ACROSS THE LIFE COURSE

REAL LIVES FOLDER



When the CoP team was established in Washington, one of their first products was a resource folder that lists supports for individuals and families. The resource folder was a result of a collaboration between the state's council on developmental disabilities, developmental disabilities agency, the Arc of WA, and others. Individuals and families, as well as professionals and organizations, can request copies of the folder at informingfamilies.org.

MYLIFEPLAN.GUIDE



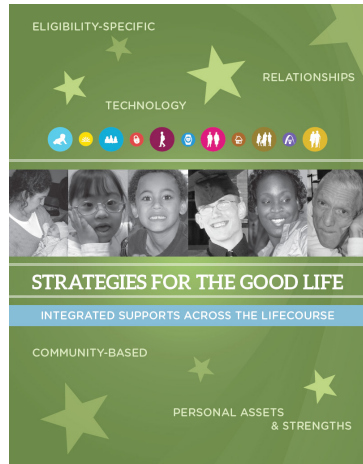
The Washington State Developmental Disabilities Council, the Arc of Washington State, and cloudPWR worked together to build an online vehicle to help guide individuals and families through planning and preparing for each stage of life. It can be accessed at mylifeplan.guide.

INFORMINGFAMILIES.ORG



REFRAMING IN MISSOURI

The CoP Team in Missouri (MO) has been updating existing materials using the LifeCourse framework. The seventh edition of the F2F Network Folder was recently released with a new color scheme and branding. The change in design was meant to nudge families and individuals toward the Integrated Supports Star and help them not focus on formal services but explore other ways of connecting with supports. The folders will be used not only by F2F and the CoP team to share LifeCourse materials but also by organizations across the state.

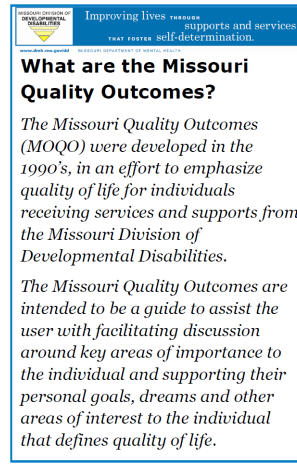


GOOD LIFE FOLDER



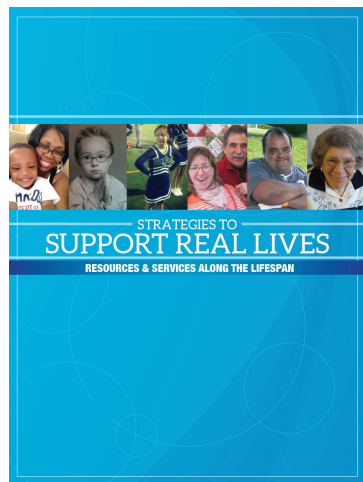
MISSOURI QUALITY OUTCOMES

Additionally, the MO Department of Mental Health Division of Developmental Disabilities recently reorganized the Missouri Quality Outcomes using the LifeCourse framework (pictured below). They are intended to be a guide to assist the user with facilitating discussion around key areas of importance to the individual and supporting their personal goals, dreams and other areas of interest to the individual that defines quality of life.



REFRAMING IN CONNECTICUT

The Connecticut (CT) CoP team has been working diligently to develop quality, accessible materials for individuals and families in their state. One of the first projects they carried out was the development of a resource folder to disseminate to families (pictured below). The next product they developed was a bookmark that outlines the goals and purpose of the CT team and the national project as well as what it means to support families. Next, sub-committees of the state CoP team worked together to develop templates for topical brochures (pictured below).



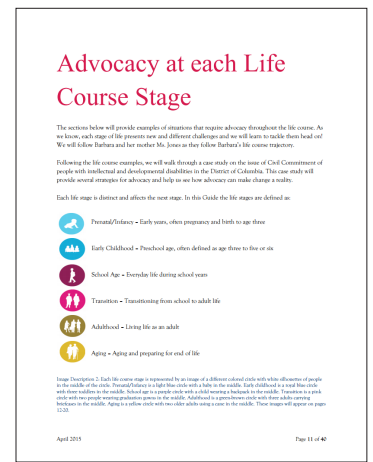
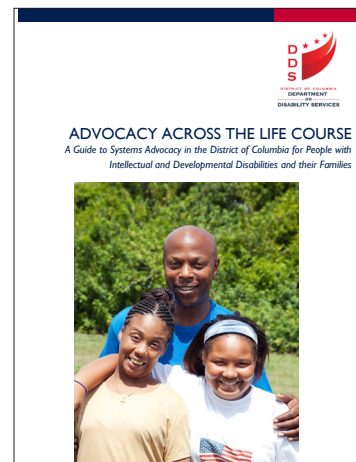
REAL LIVES FOLDER



ASSISTIVE TECHNOLOGY BROCHURE

REFRAMING IN DC

The District of Columbia (DC) CoP team has worked alongside people with disabilities, their family members and advocates to help people participate in advocacy that will change systems for many people in DC, not just one person or one family. As a result, they developed *Advocacy Across the LifeCourse* (pictured below), which uses the LifeCourse framework to talk about needs and opportunities for advocacy at different stages of life.



Visit supportstofamilies.org to connect with materials and resources from the CoP States!



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 nasddds.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 'About', 'The States', 'Resources', 'News & Events', and 'Connect'. Below this is a 'LATEST NEWS' section featuring an article titled 'Archive of the Triad Approach Innovations Series Webinar now available!'. To the right of the article is a 'FUNDED by' section listing the 'ADMINISTRATION ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES' and 'NATIONAL partners' including NASDDDS, UMKC, HSRI, ASAN, AUCC, and NACDD. At the bottom of the page is a 'MAILINGLIST' sign-up form with fields for 'First Name', 'Last Name', and 'Email Address*'. The website header includes the logo for 'SUPPORTING FAMILIES of individuals with intellectual & developmental disabilities' and the text 'THE NATIONAL COMMUNITY OF PRACTICE - FUNDED BY THE ADMINISTRATION ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES'.

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.