



# 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 (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. 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-advocacy, and sibling movements to support the entire family.

The self-advocacy, parent, and sibling movements have been working separately for many years to improve the quality of life of individuals with I/DD. 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 how Parent to Parent USA, the Sibling Leadership Network, and Self-Advocates Becoming Empowered are coming 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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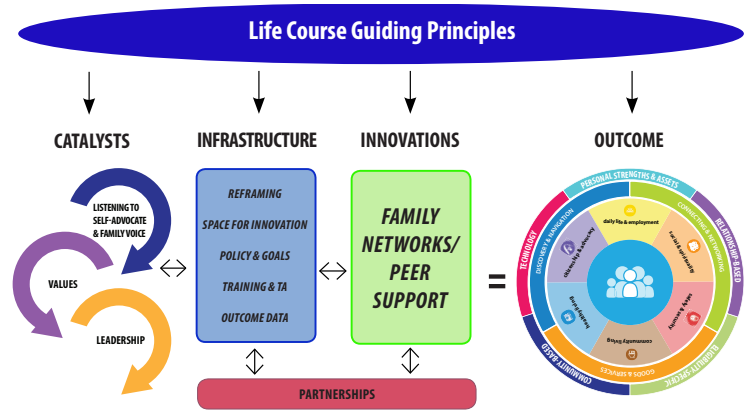
RESOURCES



**INNOVATIONS IN SUPPORTING FAMILIES**  
COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS SERIES

# THE NATIONAL COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS CHANGE

The Community of Practice (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 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](http://supportstofamilies.org).



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

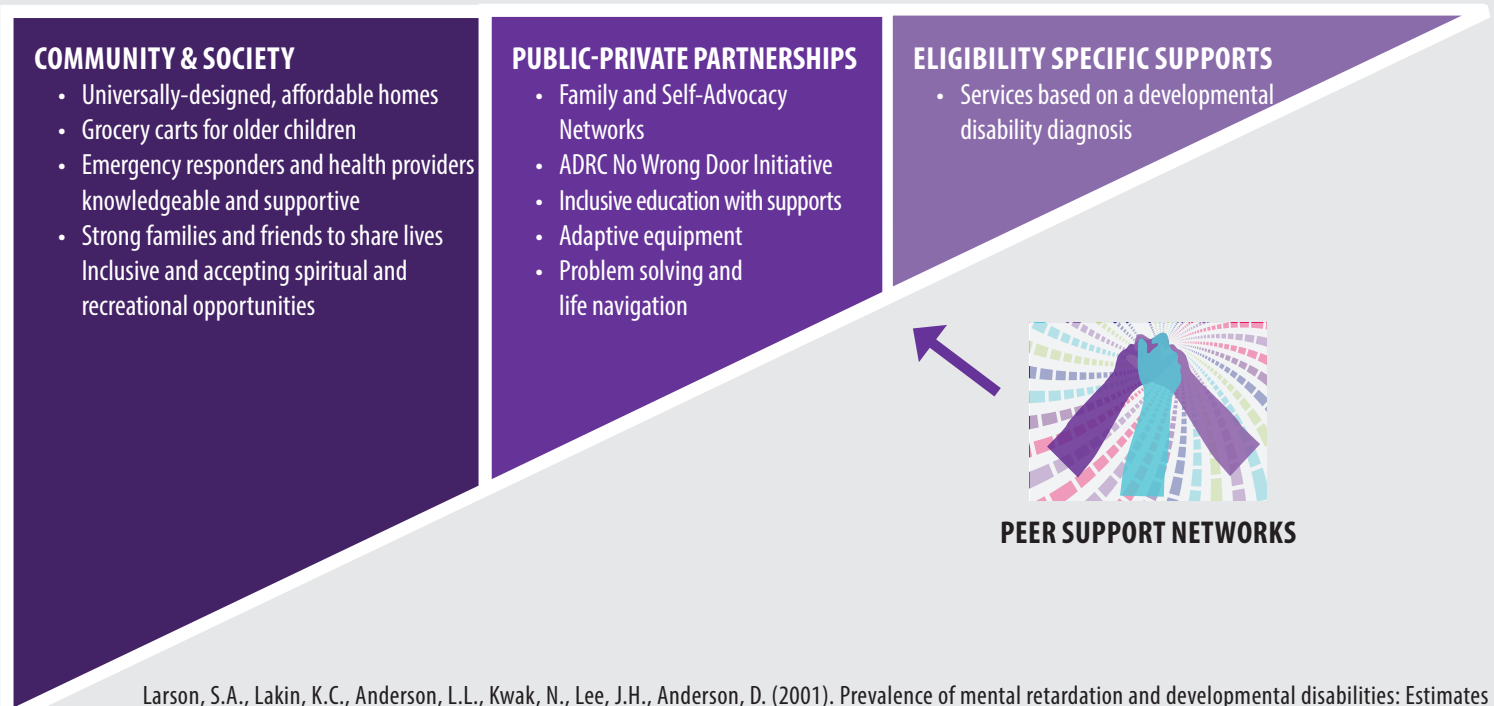
## CONNECTING FAMILIES THROUGH PEER SUPPORT

The CoP has developed a universal strategy for providing supports based on thinking, which 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 of the triangle describes policies and practices frequently used in the partnerships between public and private entities. Finally, the right region of the triangle portrays paid, formal service systems.

Currently only 25% of people with I/DD receive paid supports from the DD service system<sup>1</sup>. Federal and state budgets do not allow systems to serve all people with disabilities. So, innovative strategies are needed,

which acknowledge the changing paradigm calling for real jobs, real relationships, and real lives in the community.

Peer support is an important part of navigating life with a disability. Each of the three organizations which are part of the triad approach (Parent to Parent USA, Sibling Leadership Network, and Self-Advocates Becoming Empowered) foster peer-to-peer relationships. Connecting with another family or individual to get life questions answered, or to just have someone understand what is going on, can help individuals not feel so isolated, and possibly keep them from needing to enter the long-term services and support system.



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.



# UNITING THE MOVEMENTS FOR A GOOD LIFE

The origin of the family support movement in the disability field is rooted in the larger societal context and events of the 1950s and 1960s in the United States. The civil rights movement was starting where citizens were demanding equal rights and standards across the country. The larger social service family support movement began with the general social services movement in the 1960s, with self-help and grassroots efforts advocating for the development of community-based programs and supports to strengthen family functioning<sup>1</sup>. During this same time, the parent movement in the disability field was gaining strength and momentum. Families strongly supported the idea that their child was not broken and did not need to be removed from their home to be fixed<sup>2</sup>.

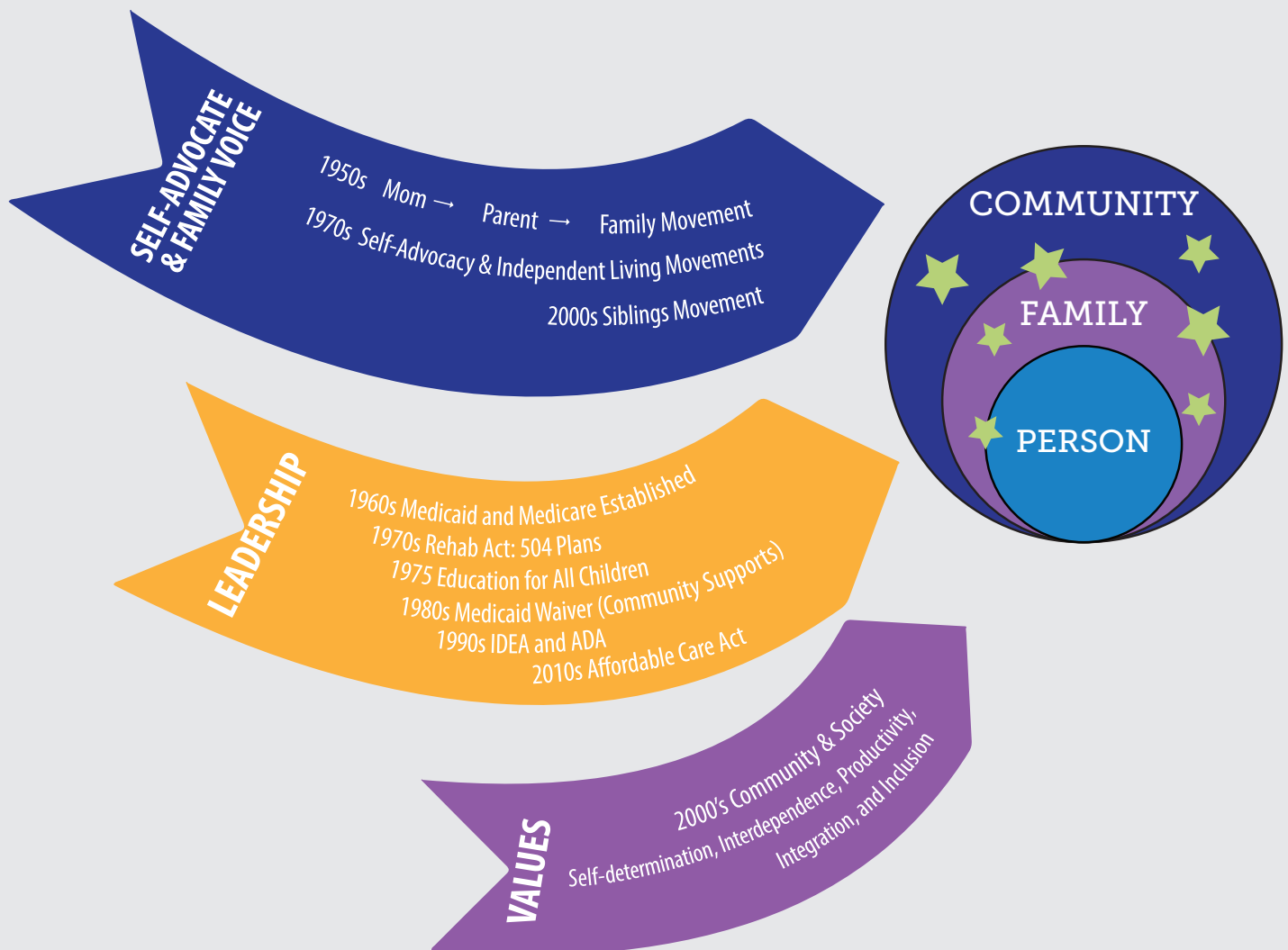
In the 70's, self-advocates rose up and proclaimed, "Nothing about me without me!" and strengthened their plea to be seen as individuals who needed support to live in the community, not people who needed to be segregated.

Much later, in the 2000's the sibling movement began to gain momentum. Generations of children were growing up with their brothers and sisters, who had disabilities, living at home. They became vocal about them being members of the community like anyone else<sup>2</sup>. Currently, the three movements are coming together in order to make a better life for the entire family. Each member is important.

## SOURCES:

1. Dunst, C.J., Johanson, C., Trivette, C.M., & Hamby, D. (1991). Family-oriented early intervention policies and practices: family-centered or not?. *Exceptional Children*, 58(2):115-126.
2. Turnbull, H.R. & Turnbull, A.P. (2000). Family support: Retrospective and prospective. In Wehmeyer, M.L. & Patton, J.R. (Eds.), *Mental Retardation in the 21st Century* (pp. 3-17). Austin, TX: Pro-Ed.

## CATALYSTS FOR CHANGE: UNITING THE MOVEMENTS FOR A GOOD LIFE



# PARTNERING TO LEAD THE CHANGE

These organizations, which represent the voices of individuals with I/DD and their families, have joined forces to form the triad approach. Learn more about them below!



[p2pusa.org](http://p2pusa.org)

## PARENT TO PARENT USA (P2PUSA)

Parent to parent support is the intentional matching of an experienced Support Parent with a parent seeking peer support. Parent to Parent USA Alliance Members are statewide organizations providing support and information to families with children who have special health care needs or disabilities, most notably through parent to parent support. Parent matches are done intentionally, and selected by a coordinator based on criteria rated by the parent in need of support. Criteria include culture, language, and other demographics. The match is followed and documented. Parent to Parent USA started in the 70's and now has chapters in many states. The vision of the organization is that all children with disabilities and special health care needs grow up in a family who supports them to lead full and happy lives in their communities.



[sabeusa.org](http://sabeusa.org)

## SELF-ADVOCATES BECOMING EMPOWERED (SABE)

SABE is a coalition of state and local self-advocacy organizations. SABE is directed by regional representatives who serve as a Board of Directors. These representatives work to connect the state and local organizations with each other for networking and resource sharing. There are nine regions, each of which elect two representatives. The idea for SABE originated at the first National People First Conference in 1990. SABE was formed later that same year. SABE grew out of a culture of individuals with disabilities working to take control of their lives. The mission of the organization is to ensure that people with disabilities are treated as equals and that they are given the same decisions, choices, rights, responsibilities, and chances to speak up to empower themselves; opportunities to make new friends; and to learn from their mistakes.



[siblingleadership.org](http://siblingleadership.org)

## SIBLING LEADERSHIP NETWORK (SLN)

SLN was established in 2007 by a small group of siblings and sibling supporters. The SLN is inclusive of siblings of people with all types of disabilities and provides support and information across the lifespan. There are over 5000 members, nationally and internationally, with 20 formal chapters and other networks. The organization's vision for the future is to see every state have a chapter. The SLN believes that by enhancing the lives of people with disabilities, the family's life is in turn enhanced. The mission is to provide siblings of individuals with disabilities information, support and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire family.

**ISSUE BRIEF** Overview of the LifeCourse Framework  
March 2015

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

Today individuals with I/DD and their families embrace the idea that people with disabilities have skills, interests, and talents like everyone else and living with their families. As practices of segregation and inclusion are reduced, a new generation of youth with disabilities are growing up to discover with their peers, going to college, getting married, and raising families of their own.

Enabling this shift in paradigm means thinking differently about what it means to support individuals with disabilities and their families. Our first community practice learning was how we have been working for the past years to clean our system away from an institutional focus to become a more person-centered system.

Thinking differently about supporting families means recognizing that people and have individual roles within a family system, which shift as the individual's number, age and sex... throughout their life.

**THE LIFE COURSE FRAMEWORK**

- History of family support
- Life Course Theory
- The National Community of Practice & the LifeCourse Framework

**RECOMMENDATIONS: RETAINING THE CONNECTION AT ALL LEVELS**

- Continuing to improve delivery
- Applying the Support for Family Practice and Planning
- Building Family & Self-Advocacy Networks
- Increasing Support of all levels
- Partnering to Develop a Coherent Message

COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS CHANGE

**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 (CP) looks for the best hope 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 continue 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 developing innovative strategies for supporting the entire family that are flexible and integrated, instead of focusing solely on formal services. The best that each or 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 between family members and the professional need for supports. Many times, the family is encouraged to engage with the service system in a way that does not meet the needs of the individual. The traditional response of professionals in the service system has been to provide families with information about services and lead them on the trajectory to viable engaging in formal services.

Changing that way that 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 the team.

**FOCUSING ON THE FRONT DOOR**

**INSIDE THIS ISSUE**

- THE NATIONAL COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS CHANGE
- INNOVATIVE STRATEGIES FOR SYSTEMS CHANGE
- FOCUSING ON INDIVIDUALS
- FOCUSING THE WORK OF THE LEAD TEAM
- INFRASTRUCTURE: RETAINING THE FRONT DOOR
- FOCUSING ON BEYOND
- INFRASTRUCTURE: RETAINING THE FRONT DOOR
- THE NATIONAL COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS CHANGE
- COMMUNITY OF PRACTICE LEARNING

**VISIT**  
**SUPPORTSTOFAMILIES.ORG/INNOVATIONS**  
to view all *Innovations* series materials, including archived webinars and previous issue briefs!



# THE TRIAD APPROACH: UNITING THE MOVEMENTS FOR A GOOD LIFE

## THE DEVELOPMENT OF THE TRIAD APPROACH

Sibling Leadership Network has partnered with Self-Advocates Becoming Empowered since its inception. The pair reached out to Parent to Parent USA in order to engage in conversations about advocating for individuals with disabilities and how to move forward. The dialog began in 2013, when the three organizations worked to learn from each other and work together to make meaningful change. While the triad approach highlights the unique connection between parents, self-advocates, and siblings, these organizations recognize that all members of the family matter and welcome information and partnerships from other advocacy organizations that may focus on other family members, such as grandparents.



## THE TRIAD APPROACH AT THE NATIONAL LEVEL

The triad approach is about building stronger relationships and collaborations. When supports, services, programs, etc., are designed, it is imperative that all members of the family be taken into account, not just the person receiving services. The perspective of all individuals in the family are important, and the three organizations in the triad bring them together to empower the entire family unit. The triad works to share a common vision for the future around disability supports and services, at the individual, practice, and policy levels. Professionals can offer many important perspectives and services however language, viewpoint, and day-to-day experiences differ from the perspective of the twenty-four hour reality of family members.

Peer-to-peer mentorship is a strong focus of all three organizations. The vision for the future is for parents to get connected to each member of the triad upon getting the diagnosis for their child; the support can make an amazing difference for the entire family. Peer to peer mentorship does look different for every member of the family, and support needs to respect those differences. The triad perspective helps

people learn from one another what is meaningful and necessary to all three groups; parents, self-advocates, and siblings.

## LOOKING TOWARDS THE FUTURE

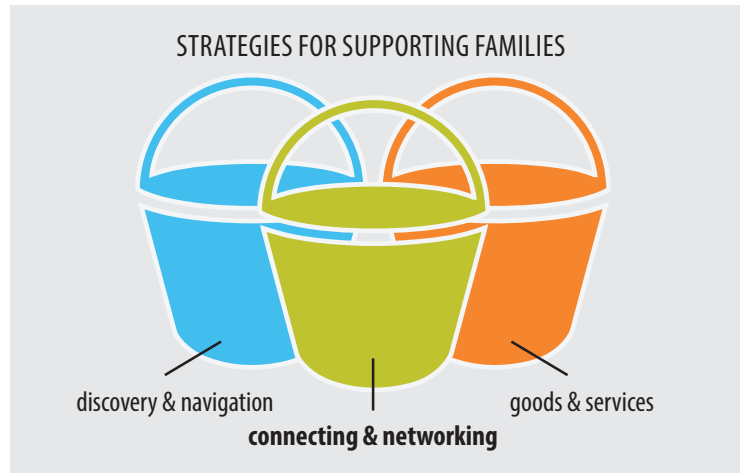
Families respond when others outside of their own unit bring them new information. Hearing from others can open their eyes, and allow them to learn. Understanding unique perspectives is imperative. Building partnerships within each state is a great activity to be supported through the triad and the Community of Practice. When all family members come together, they have amazing power as advocates. Through the triad, meaningful and valuable change is happening.



# LEARNING FROM THE NATIONAL COMMUNITY OF PRACTICE

## OVERALL

**Connecting & Networking.** Connecting and networking is one strategy for supporting families, which includes peer support, self-advocacy and family organizations, sib-shops, support groups, and professional counseling. Also included are non-disability community support which may access to enhance their mental health and self-efficacy. Matching a family with other families, including parents with disabilities, self-advocates and siblings, grandparents and others for mutual support has been found to have significant benefits for both the person receiving the support and the person offering the support. Find out what is happening in some of the CoP states around connecting families with other families.



### DISTRICT OF COLUMBIA

As a result of their participation in the Community of Practice and their change in thinking about supporting families, the District of Columbia (DC) team has been working on offering more to families in the way of connecting and networking. The team partnered with Parent to Parent USA to develop a P2P chapter in DC which will offer ongoing peer to peer support. The DC team is working to establish sustainable funding for the chapter and joining with interested parties to get the chapter going for families.



### CONNECTICUT

Connecticut's state developmental disabilities agency is taking a new approach to peer support through technology. A partnership was born out of the Connecticut CoP team's focus on technology. The agency teamed up with Tyze to offer online peer support to individuals and families who use self-directed supports through the state agency.

Tyze is an online tool which helps people care for others, with no cost to the user. Tyze is much like a social media site and was selected because of the affordability and ease of use of the software. While Connecticut is using it specifically for people with disabilities and their family members, it is a tool that anyone with a need for caregiving support could use.

Connecticut rolled out the use of Tyze earlier this year. In the few months since it has been available, it has been growing in use and popularity among recipients of DD services in the state. This growth is seen because of the information people are receiving about it. Individuals who self-direct their services are getting e-newsletters and information blasts that not only contain information on peer support, but information on how to utilize Tyze to get peer support.

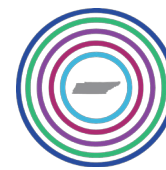


### MISSOURI

Missouri Family to Family's (MOF2F) peer support program was designed to build on Parent to Parent's model. The program is an offering of the statewide Health Information Center, housed at Missouri's University Center for Excellence in Developmental Disabilities, the UMKC Institute for Human Development. The program serves individuals with I/DD, family members, and even professionals. The Missouri Family to Family network hosts a cadre of almost 600 trained, volunteer parent mentors who serve as a crucial support to parents in need. The match criteria is based on the standards developed by P2P USA.

MOF2F receives requests for peer support by parents who self-refer for support or from affiliate organizations serving families. These organizations offer it as a supplemental support while families are waiting for services or to augment the quality of services received. The mentor match is followed by staff at MOF2F and satisfaction data is collected to ensure timely and productive support.

MOF2F's goal is to connect individuals to another self-advocate, parent, or family member who can help them navigate life and answer questions, while providing hope for the future.



### TENNESSEE

In Tennessee, the DD Council has been hosting various topics in a series of Lunch-and-Learn workshops. One of these Lunch-and-Learn sessions focused on peer support. Attendees learned about the Community of Practice, then about the value of peer support, and the different kinds of peer support, from informal to formal. Attendees also heard about smart practices in peer support happening in other states with established peer support networks.



# The LifeCourse Framework

## REFRAMING OUR THINKING TO ENHANCE SUPPORTS TO FAMILIES

The LifeCourse framework that was developed 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 but may also find it helpful to look ahead to start thinking about what they can do or learn now that will help build an inclusive 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 citizen 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.

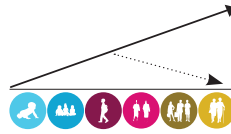
### LIFE COURSE FRAMEWORK/PRINCIPLES

#### 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 will be hosted live every other month beginning January 2015 and archived for later viewing at [nasddds.org](http://nasddds.org) and [supportstofamilies.org](http://supportstofamilies.org).

Learn more about the series at [supportstofamilies.org](http://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 the navigation bar, there is a 'LATEST NEWS' section with a featured article titled 'Archive of the Triad Approach Innovations Series Webinar now available!'. To the right of the news section, there 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 screenshot, there is a 'MAILING LIST' 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](http://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.