

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

We're All in this Together:
Uniting the Movements for
a Good Life

JUNE 25, 2015



NASDDDS

UMKC
INSTITUTE FOR HUMAN DEVELOPMENT
A University Center for Excellence in Developmental Disabilities (UCEDD)

HSRI



SUPPORTING FAMILIES

of individuals with intellectual & developmental disabilities

THE NATIONAL COMMUNITY OF PRACTICE • FUNDED BY THE ADMINISTRATION ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES

Project Goal

To build capacity through a community of practice across and within States to create policies, practices and systems to better assist and support families than include a member with I/DD across the lifespan.



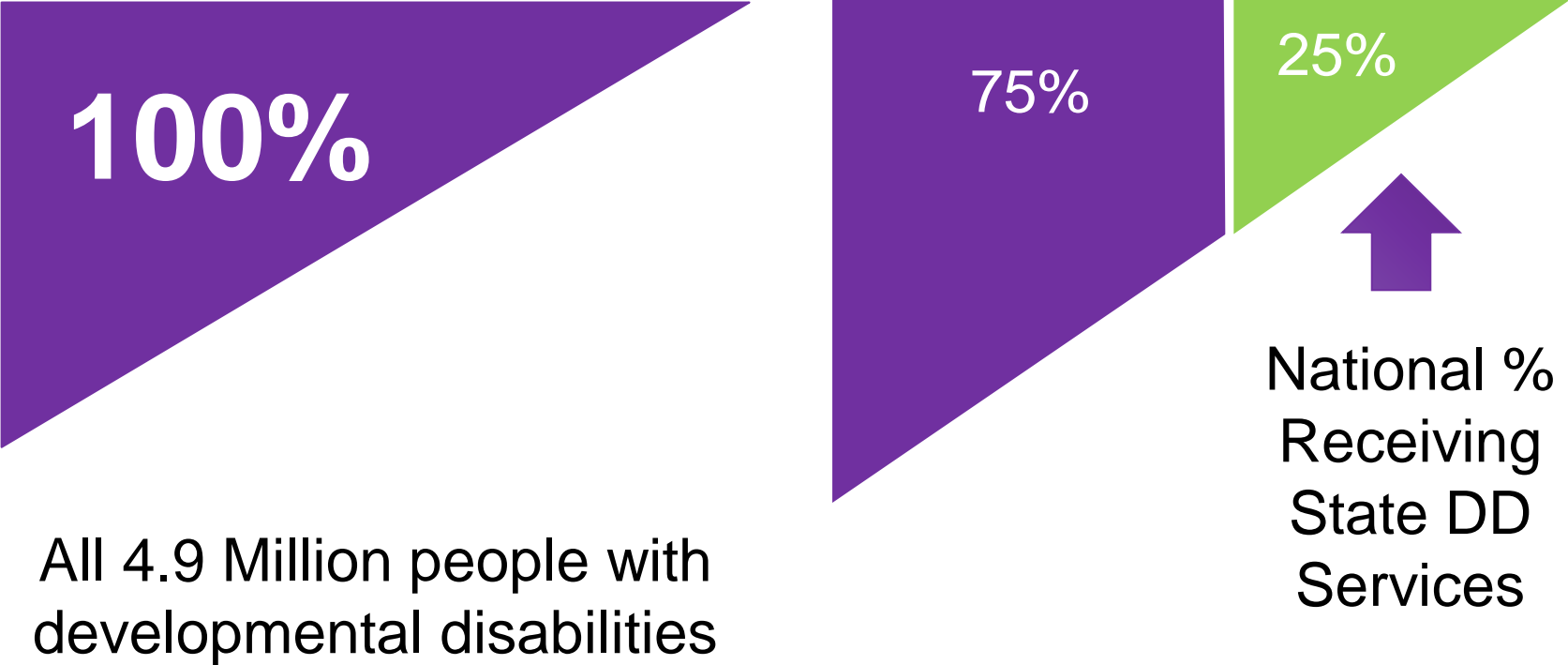
ADMINISTRATION ON
INTELLECTUAL AND
DEVELOPMENTAL
DISABILITIES



All people have the right to live, love, work, play and pursue their dreams in their community.



Focus on “ALL”



*** Based on national definition of developmental disability with a prevalence rate of 1.49%*

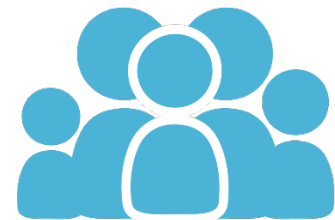
“Good Life for All ”



The Individual will achieve self-determination, interdependence, productivity, integration, and inclusion in all facets of community life



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



Focusing on Person & Their Family



**All individuals live within the
context of a family.**

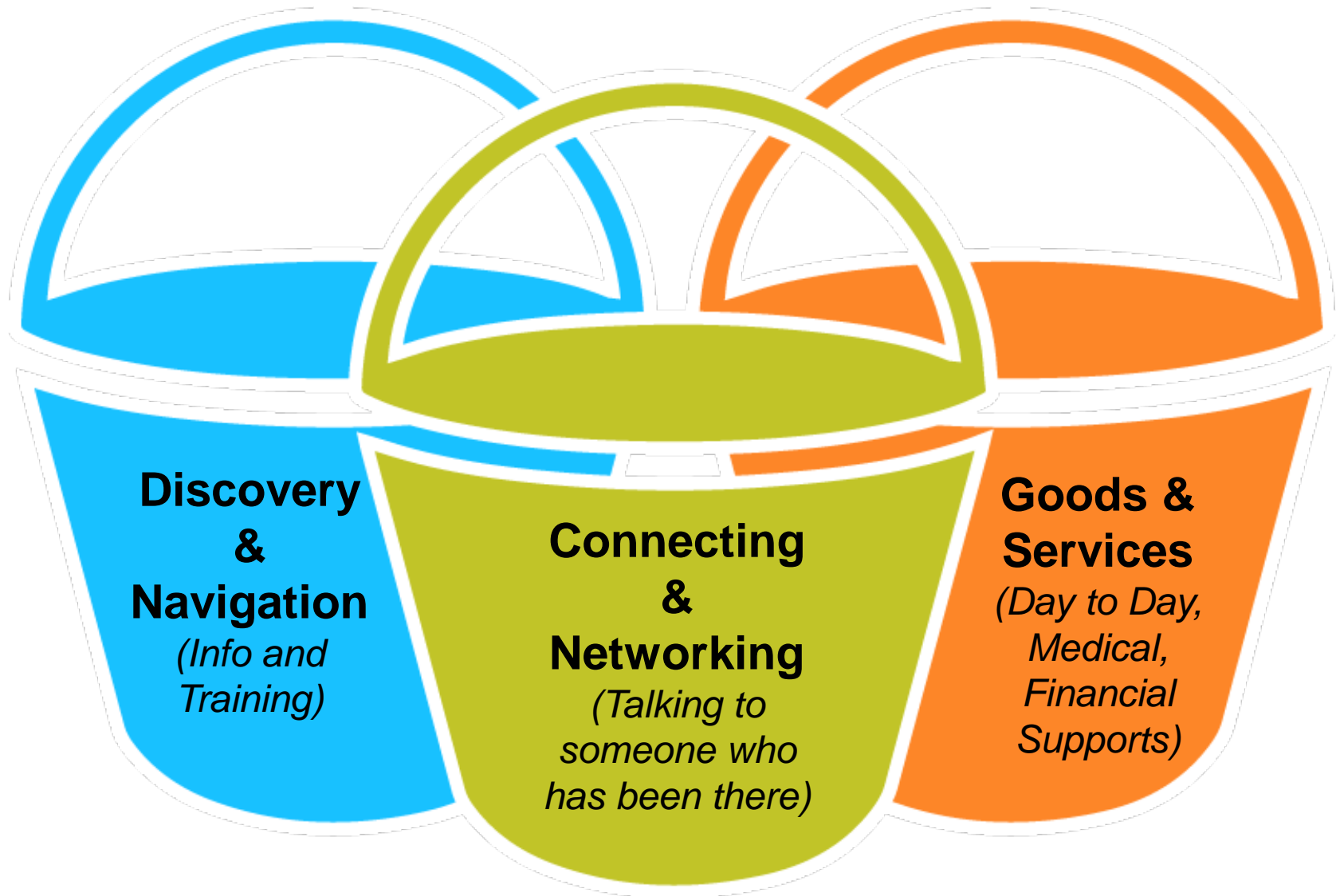
(Regardless of where a person lives)

Reciprocal Roles of ALL Family Members

 Caring About	Affection & Self-Esteem
	Repository of knowledge
	Lifetime commitment
 Caring For	Provider of day-to-day care
	Material/Financial
	Facilitator of inclusion and membership
	Advocate for support

**Adapted from Bigby & Fyffe (2012), Dally (1988), Turnbull et al (2011)*

Three Types of Supports



Partnering with Person with Disability
and their Families so they can
Engage, Lead, and Drive
Their Own Lives and
Policy and Systems Change



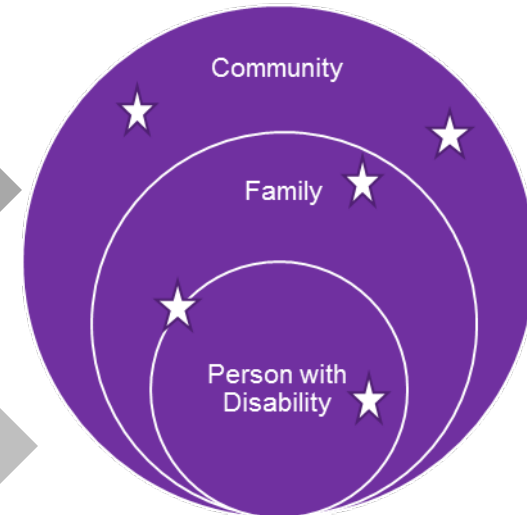
Uniting the Movements for a Good Life

1950s Mom-----Parent-----Family Movement
1970s Self-Advocacy and Independent Living
Movements (Not about me, without me)
2000s Siblings Movement

1960s Medicaid and Medicare Established
1980s Medicaid Waiver (Community Supports)
2010s Affordable Care Act

1970s Rehab Act: 504 Plans
1975s Education for All Children
1990s IDEA and ADA

2000's Community
and Society





The Triad Approach: Perspectives from Each Organization

Triad Approach

Self-Advocates, Parents and Siblings make up the triad

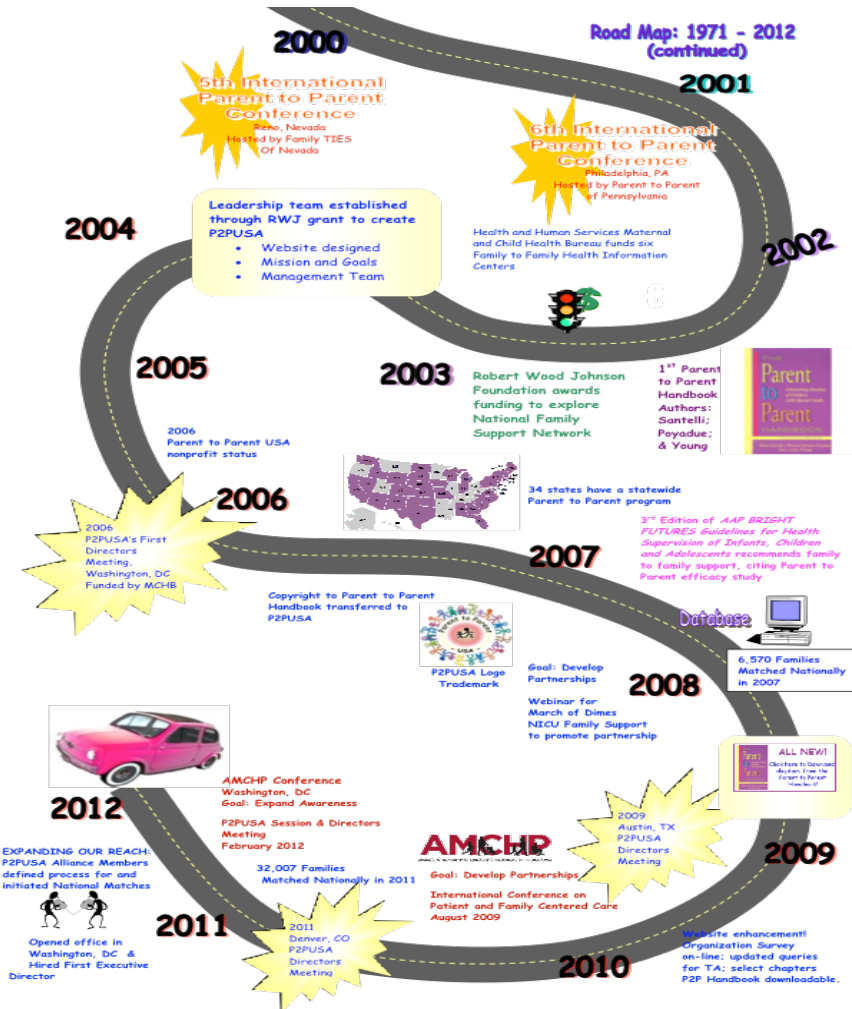
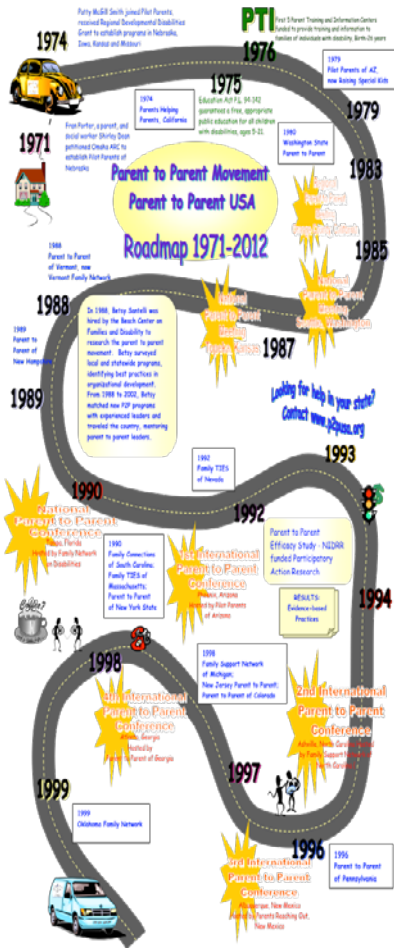




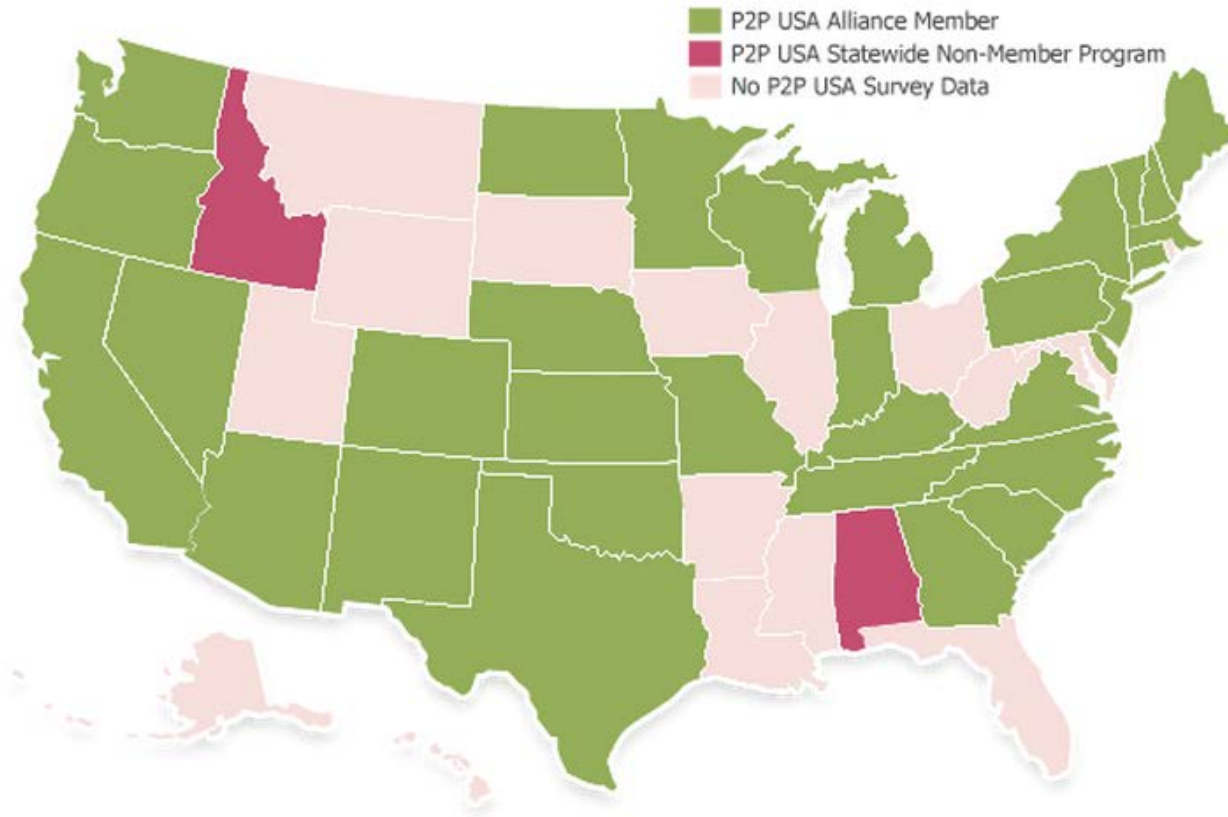
Parent to Parent Basics

- Parent to parent support, is the intentional matching of an experienced, prepared, 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.

P2P Roadmap



Where are the chapters?



Go online to www.p2pusa.org to find your state's chapter!

Why is family support important?

- Statistics clearly show impact on families
- Families should be healthy, happy, and strong at every stage throughout the life course; our needs change regularly!



What is the role of family support?

P2P USA's vision:

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.





Don't Forget the Siblings!

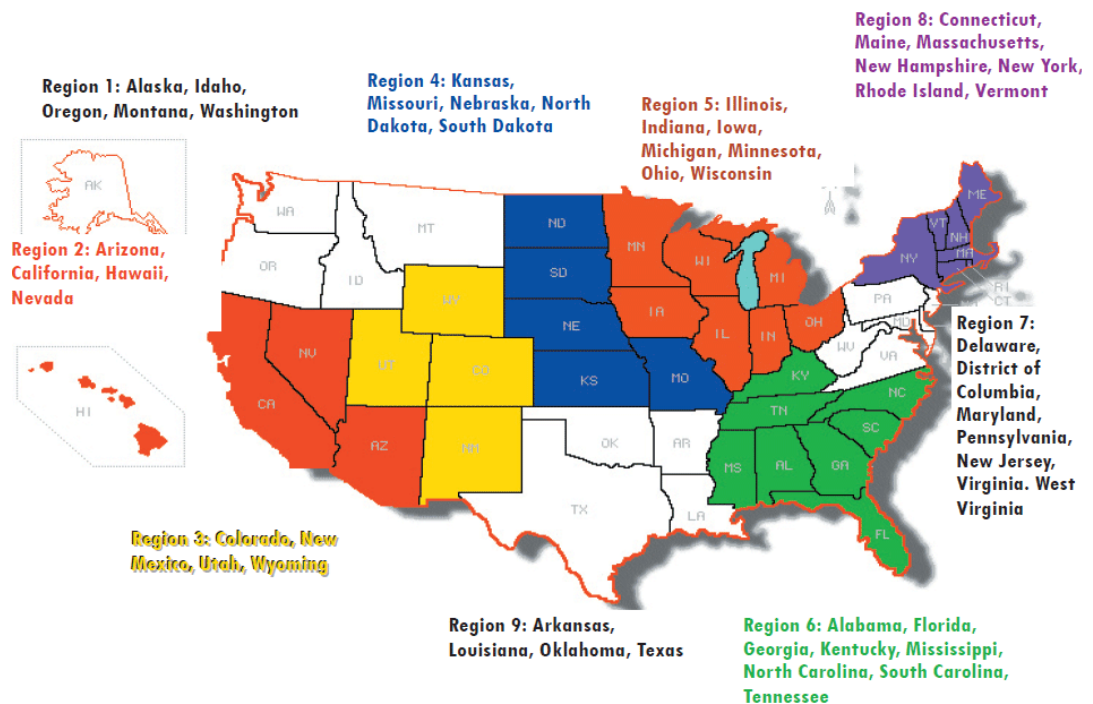
Growing Self-Advocacy Skills through Peer Support



Self-Advocates Becoming Empowered (SABE)



- Est. 1990
- National organization with an executive committee and 2 regional representatives from nine regions, that serve on the national board



SABE



- Even though self-advocacy hasn't always been well received by professionals and family members, family support is important to SABE because they recognize everyone belongs to a family.
- The Triad Approach will help our organizations to learn about each other and begin working together.

Sibling Leadership Network



Mission: *Provide siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families.*

Inclusive of siblings of people with ALL types of disabilities and provides supports and information across the lifespan



SLN Chapters



Oklahoma Supporting and Including Brothers and Sisters



Georgia Sibling Connection



Ohio SIBS



Sibling Leadership Network

- Why is family support important to siblings?
 - Family Support vs. Supporting Families
- What is the role of family Support?
 - Holistic perspective
 - Strengthen the family system – ultimately
 - Improving quality of life for all members



Sibling Leadership Network

Getting Involved

- Join the national network
- Identify state chapter
- SLN Committees
 - *Policy and Advocacy*
 - *Research*
 - *Communications*
 - *Chapter Development*
 - *Support & Information*
- Participate in the dialog



www.siblingleadership.org

What are they saying about family support?

Parent to Parent (P2P):

Each family, and each individual in that family, has unique needs for support, and unique perspectives; we must all (families/professionals) work together to create individualized, quality support to families

SABE

(Video from SABE conference)

Sibling Leadership Network:

Unique perspectives yet all working toward a common goal



The Triad Approach at the National Level

The Triad Approach at the National Level

- Building stronger collaborations
- Sharing with others the importance of collective family empowerment
- Identifying opportunities to share with others the importance of including all members of the family with supports and future planning
- Professionals can, and do, offer many important services, but language, viewpoint, and day to day experiences differ from the 24-hour reality of family members

The Triad Approach at the National Level

Peer-to-Peer Mentorship

- Parent to Parent
- SABE
- *SIB2SIB*

Pilot program supported by the NIDILRR funded Family Support Research and Training Center awarded to the Institute on Disability and Human Development at University of Illinois at Chicago.

 - Learning Community
 - Three pilot states – Colorado, Massachusetts and Wisconsin

Looking to the future

- Listen carefully to understand the unique perspectives of all family members
- Build partnerships within your state
- Start the conversation
- Individual Family empowerment through collaborations



Questions, Reflections and Discussion

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Innovations Webinar Series

Archived webinars:

Overview of the LifeCourse Framework

Focusing on the Front Door of Long Term Services & Supports

Future topics:

National & State Data Projects

Person-Centered & LifeCourse Planning

Medicaid Waivers and Other Funding Sources

Waitlist for Services

ISSUE BRIEF

Overview of the LifeCourse Framework
March 2015

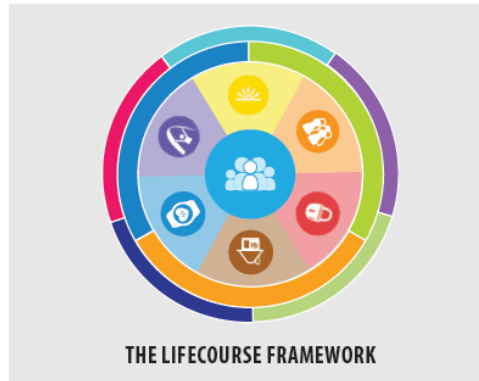
All people have the right to live, love, work, play and pursue their life aspirations in their communities.

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 I/DD 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 hard 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.



INSIDE THIS ISSUE

BACKGROUND: SUPPORTING FAMILIES AND THE LIFECOURSE

- History of Family Support
- Life Course Theory
- The National Community of Practice & the LifeCourse Framework

RECOMMENDATION: REFRAMING THE CONVERSATION AT ALL LEVELS

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

COMMUNITY OF PRACTICE LEARNING

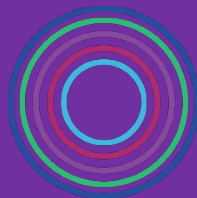
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ISSUES BRIEF

Overview of the LifeCourse Framework



INNOVATIONS IN SUPPORTING FAMILIES
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 (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 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 supports. 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.



FOCUSING ON THE FRONT DOOR

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THE NATIONAL COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS CHANGE

INNOVATIVE STRATEGIES FOR SYSTEMS CHANGE

FOCUSING ON TENNESSEE

SEIZING THE MOMENT: THE LEAN EVENT

INFRASTRUCTURE: REFRAMING THE FRONT DOOR

FOCUSING ON MISSOURI

INFRASTRUCTURE: REFRAMING THE FRONT DOOR

PARTNERSHIPS: MEETING FAMILIES AT THE FRONT DOOR

COMMUNITY OF PRACTICE LEARNING

THE LIFECOURSE FRAMEWORK

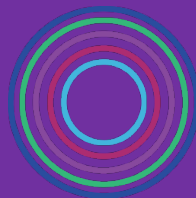
RESOURCES



INNOVATIONS IN SUPPORTING FAMILIES
COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS SERIES

ISSUES BRIEF

Front Door to Long Term-Services & Supports





SUPPORTING FAMILIES

of individuals with intellectual & developmental disabilities

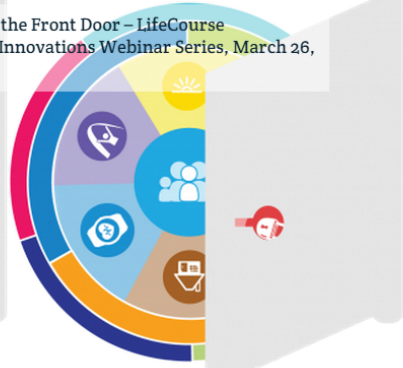
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Joining Forces TV coverage in Oklahoma!

LATESTnews

Focusing on the Front Door – LifeCourse Framework Innovations Webinar Series, March 26, 2015



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ADMINISTRATION ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

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Welcome!

The Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities involves working with six states to develop systems of support for families throughout the lifespan of their family member with intellectual and developmental disabilities (I/DD).

The Supporting Families project is operated under a five year grant awarded to NASDDDS by the Administration on Intellectual and Developmental Disabilities (AIDD) beginning October 2012. Grant partners include University of Missouri Kansas City-Institute on Human Development (UMKC-IHD), Human Services Research Institute (HSRI) and the National Association of Councils of Developmental Disabilities (NACDD).

MAILINGlist

Get updates about the national project, state teams, and supporting families!

First Name

Last Name

Email Address*

Print, Facebook, Email, and a plus sign for more options.

Visit us online at supportstofamilies.org