

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

**Reframing the  
Conversation at All  
Levels:  
Tools for Change**

AUGUST 27, 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

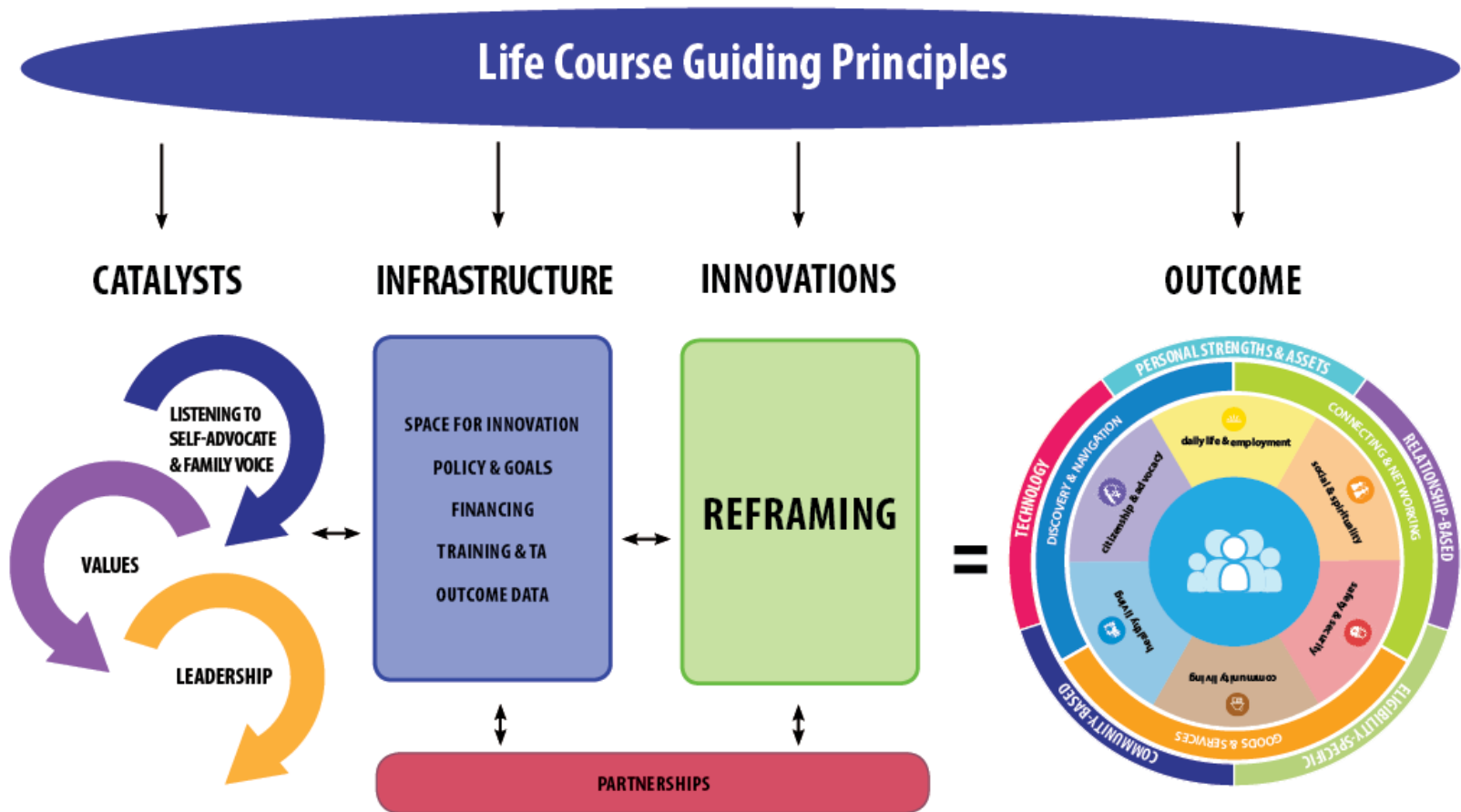
## Project Goal

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

# National CoP for Supporting Families Framework for Systems Change

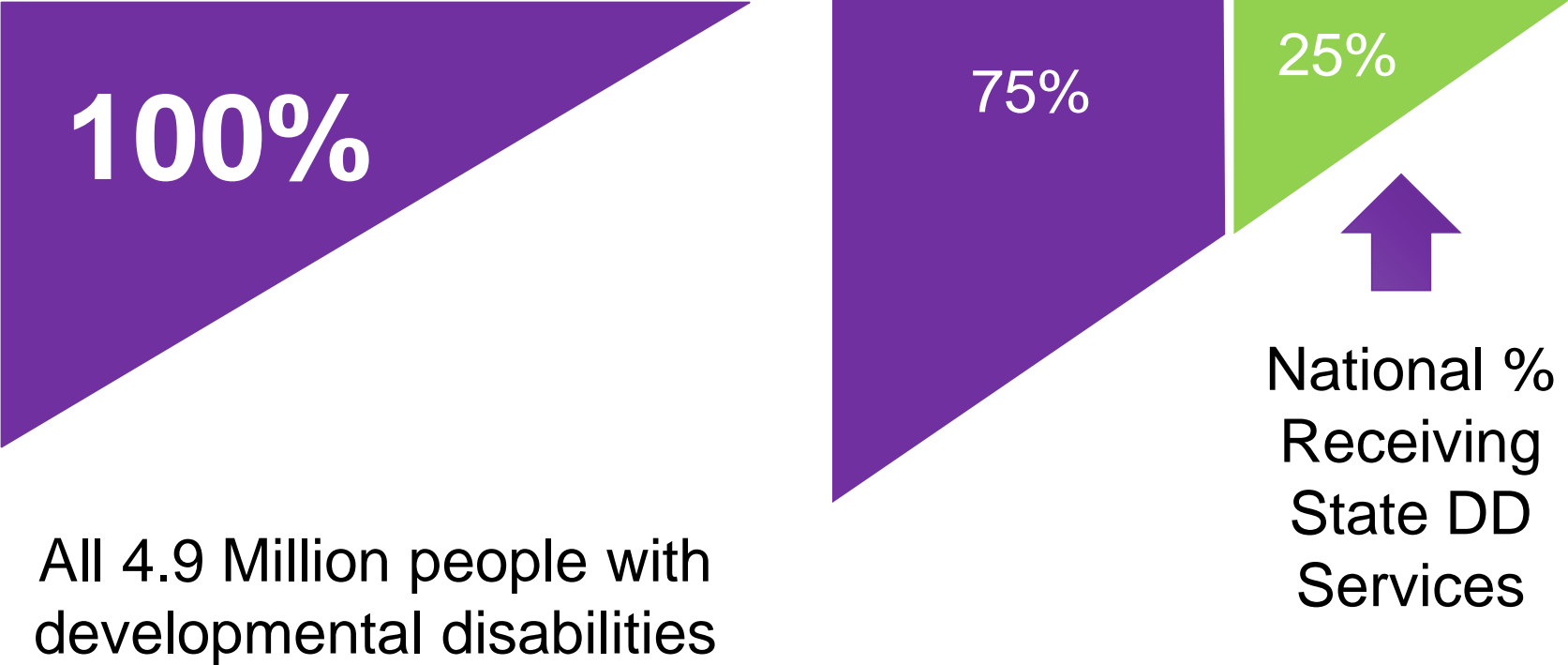




All people have the right to live, love, work, play and pursue their dreams in their community.



# Focus on “ALL”



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

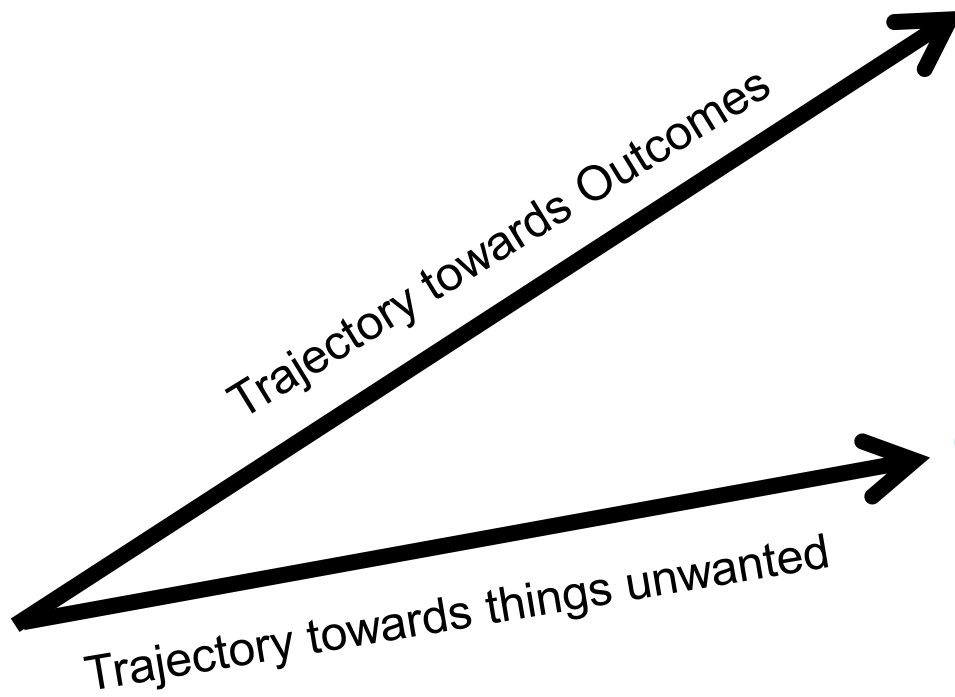
# Focusing on Person & Their Family



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

*(Regardless of where a person lives)*

# Trajectory towards Life Outcomes



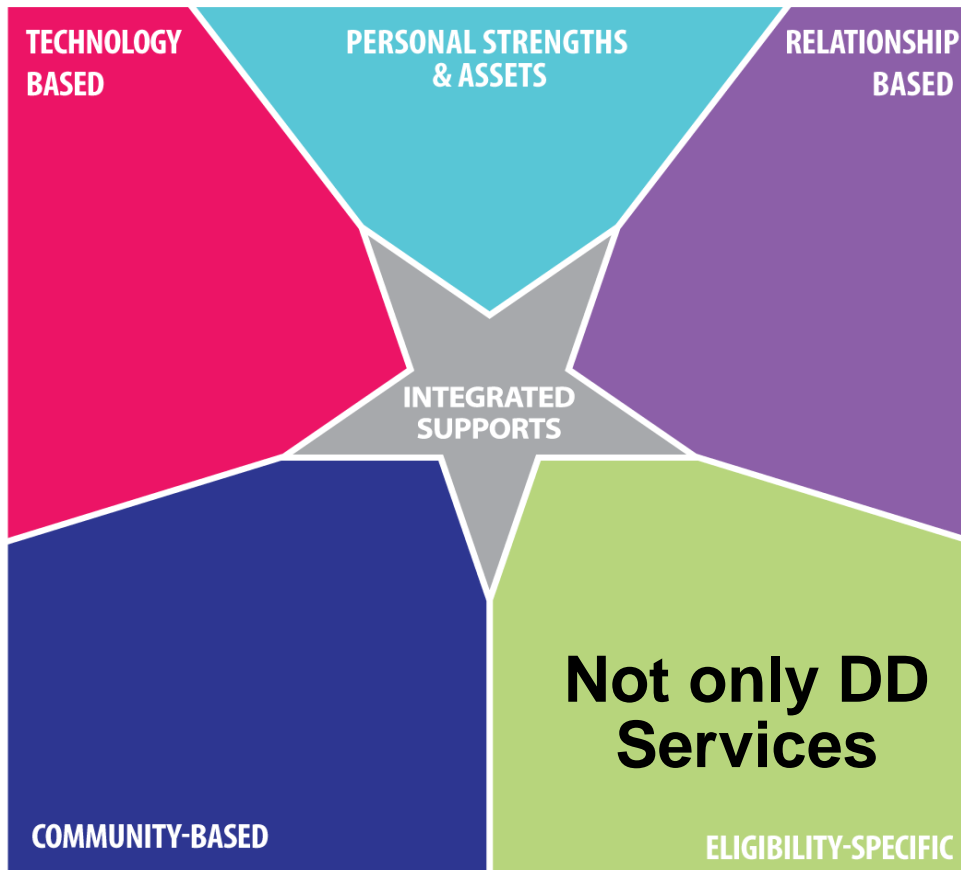
*Friends, family, self-determination,  
community living,  
social capital and  
economic  
sufficiency*

**Vision of What I Don't Want**



*Both in practice with individuals and  
in policy changes for systems*

# Identifying Integrated Strategies for Delivery Supports

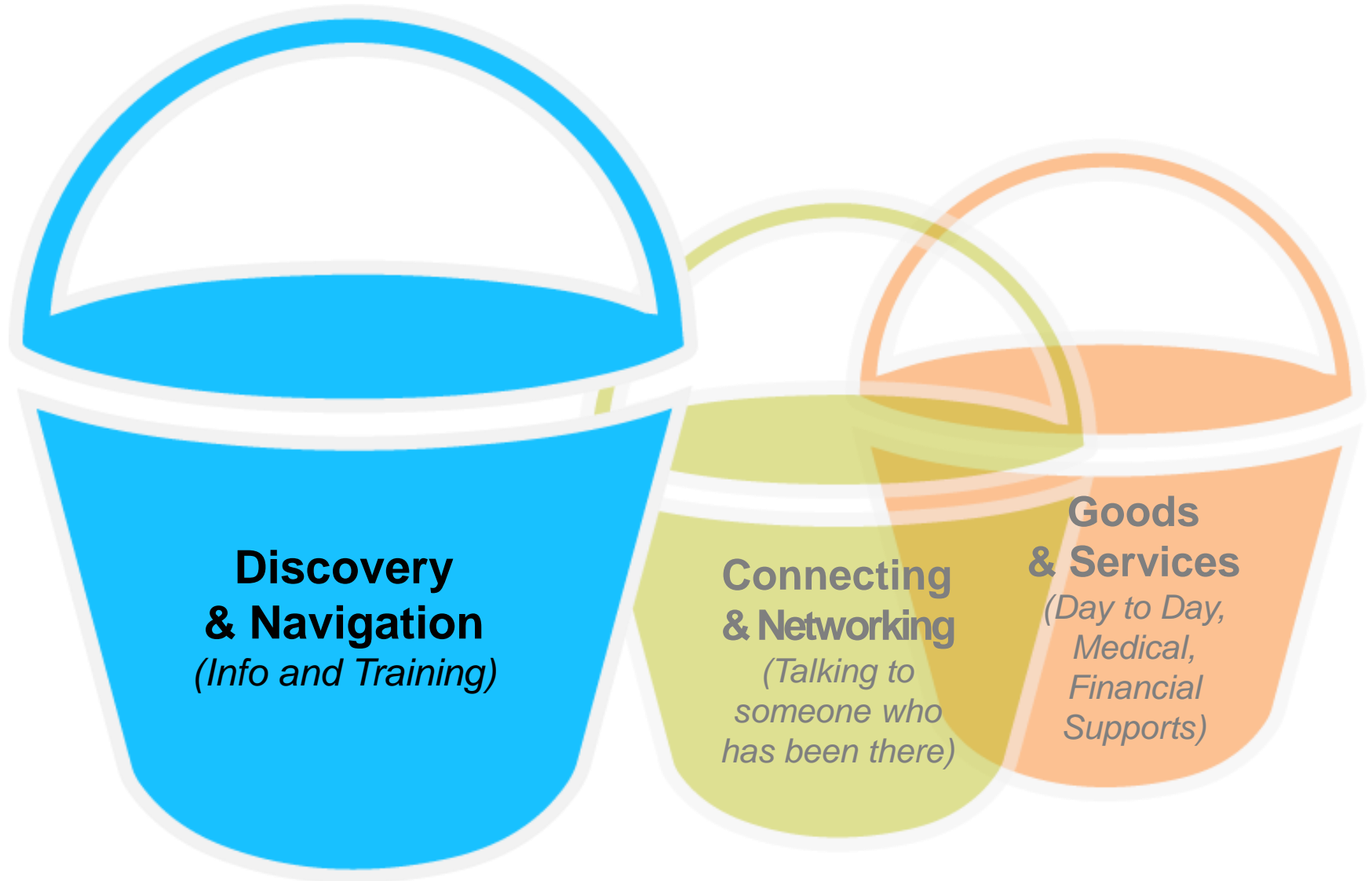




Partnering with Person with Disability  
and their Families so they can  
Engage, Lead, and Drive  
Their Own Lives and  
Policy and Systems Change



# Three Types of Supports



# Outcomes for Today's Webinar

- Understand the concept of 'reframing' and how it is taking place in the DD field across the nation
- Learn the basics of executing a communications strategy that reaches multiple target audiences
- View specific reframing efforts taking place in CoP states
- Explore your questions and ideas for improvements in your state with national and state CoP members



**Why Reframing?**

# Change that is Needed

## TRANSITIONAL CHANGE

“Retooling” the system and its practices to fit the new model

Mergers, consolidations, reorganizations, revising systematic payment structures,

Creating new services, processes, systems and products to replace the traditional one

## TRANSFORMATION CHANGE

**Fundamental reordering of thinking, beliefs, culture, relationships, and behavior**

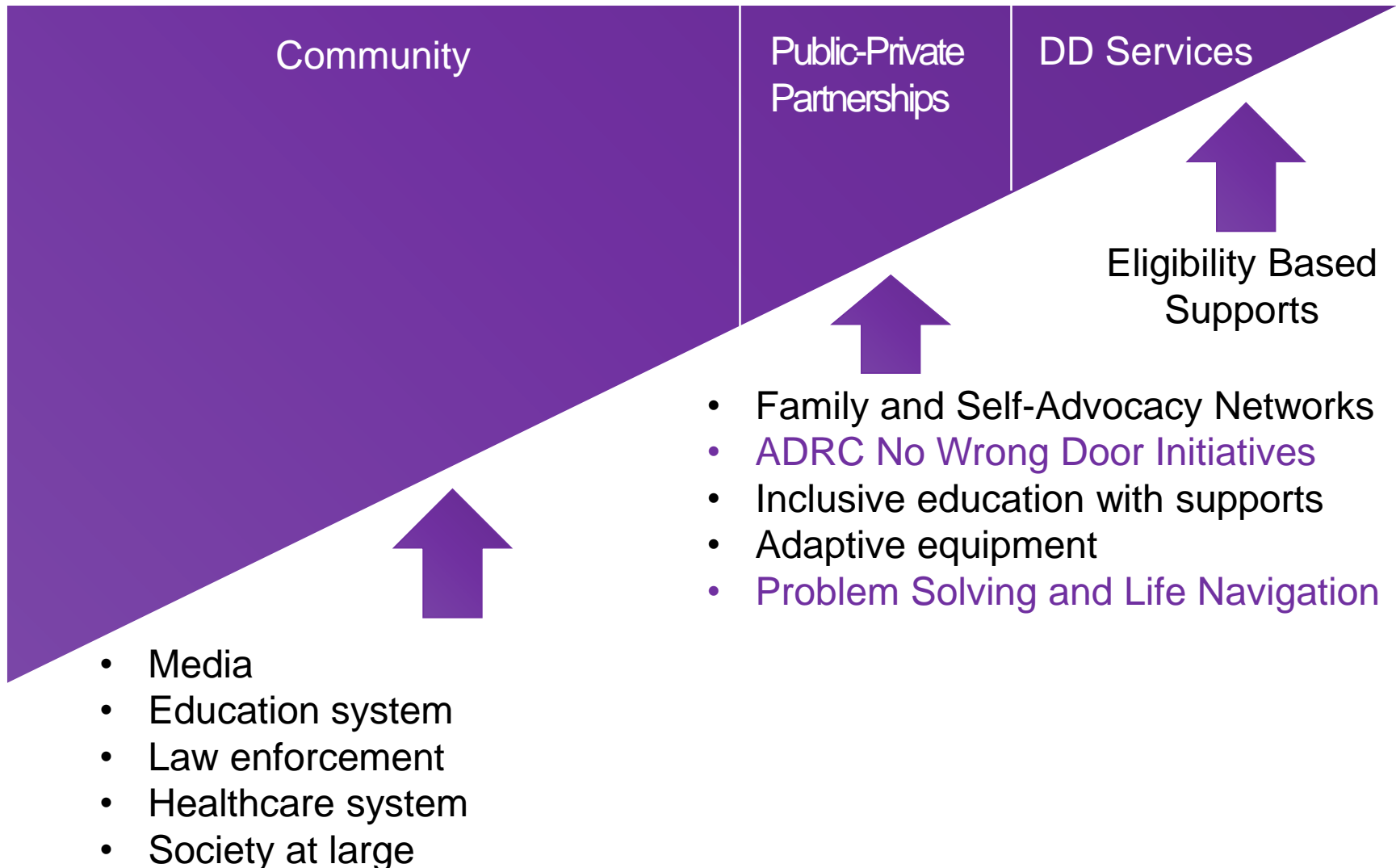
**Turns assumptions inside out and disrupts familiar rituals and structures**

**Rejects command and control relationships in favor of co-creative partnerships**

*Creating Blue Space, Hanns Meissner, 2013*



# Focusing Reframing Strategies





# Strategic Communications 101

# Communications Bosses...

1. Think strategically about communication
2. Use a mix of different mediums
3. Constantly monitor and evaluate efforts for success
4. Are reverent to technology



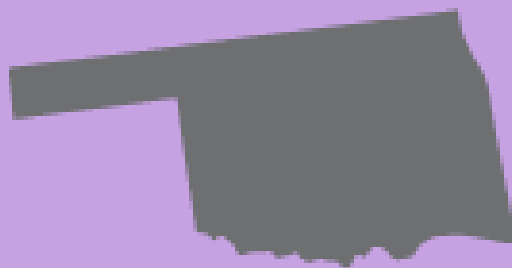


# Methods to the Madness

The key ingredients in a strategic communications plan

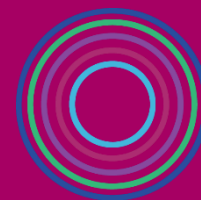
- Goals
- Messages
- Audiences
- Partnerships
- Plan (Channels and activities)
- Evaluation





# Oklahoma

**Ann Trudgeon, Executive Director**  
OK Developmental Disabilities Council



# Oklahoma's CoP Team

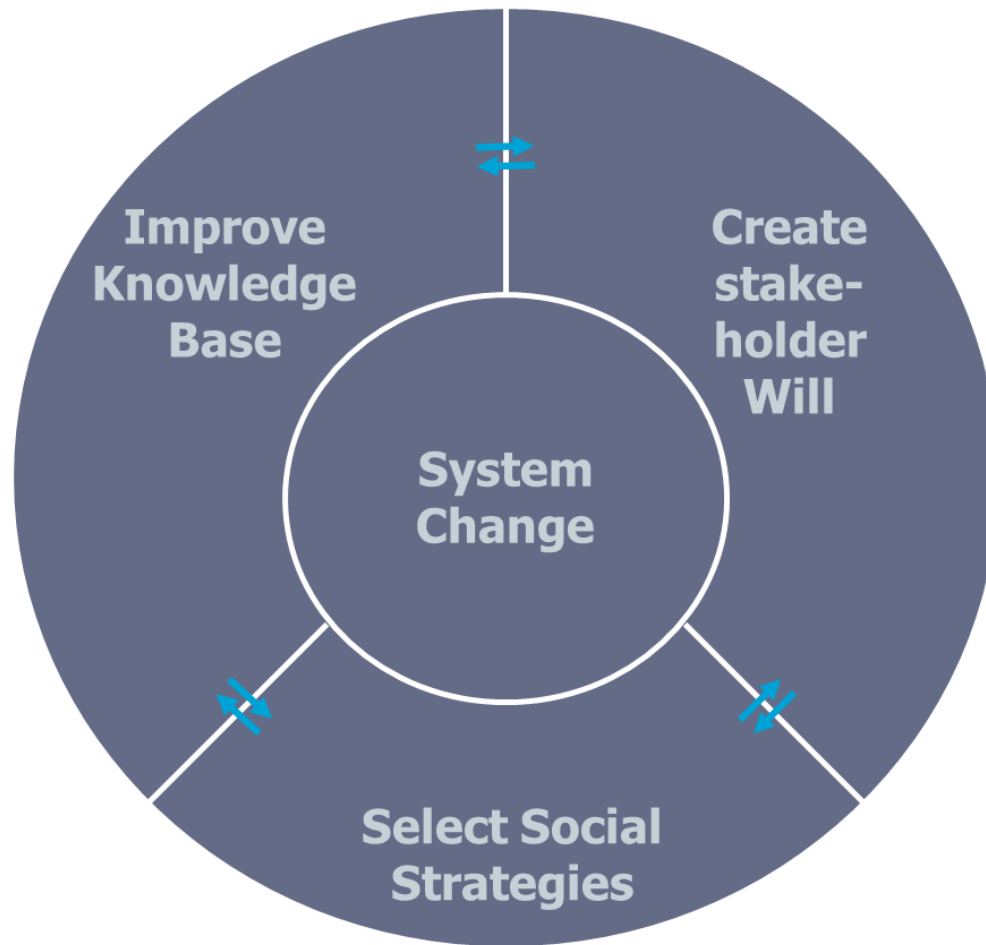
Slow and steady build – took the opportunity to really learn the tools and philosophy before deciding on a course of action

Open to any partners – individuals and organizations, but walking through open doors – not beating any down (yet)

Using the Route to Success model to plot systems change



# Route to Success



# Route to Success Matrix

Create Knowledge Base	Select Social Strategies	Create Stakeholder Will	Support Policy Entrepreneurs	Use Unexpected Events
Plot people, objectives, and achievements				

**Create knowledge base:** What are the current problems, trends, unmet needs? What are potential solutions – or actual solutions that are not being used systems-wide? How do we reach out to potential partners and what do we say/present to them?

**Select Social Strategies:** What will we do? Establish clear goals and methods for achieving them. Identify key players. Analyze constraints. Articulate responsibilities. Evaluate results. Celebrate success.



# Route to Success Matrix, cont.

**Create Stakeholder Will:** Who are your collaborators? Who will do the work? Who cares about the problem? Is there an existing constituency? Is there political will? Is there work to be build upon? Does it appear to be too complex? Is there a sense of urgency?

**Policy Entrepreneurs:** Champions. Change agents. Connections. KEY to sustainable change.

**Unexpected Events:** Be prepared to seize on opportunities like a budget cut or surplus, significant news item, etc.



# Publications

- Oklahoma CoP LifeCourse book
- Oklahoma Guide to Community Services
- Resource Folder
- Brochures for DD Council and DDS frame around “a good life”



# OK Resource Folder



## PARTNERING FOR A GOOD LIFE

CONNECTING WITH SUPPORTS IN OKLAHOMA





# Guide to Community Services in Oklahoma

*for People with Disabilities and Their Families*

May 2014  
Edition



**Center for Learning  
and Leadership**

A University Center for Excellence  
in Developmental Disabilities

 The UNIVERSITY of OKLAHOMA  
**Health Sciences Center**

# Guide to Community Services



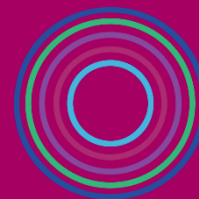
# Partnering for a Good Life

IN-HOME SUPPORTS WAIVER



Developmental  
Disabilities  
Services

## DDS Brochure Sample

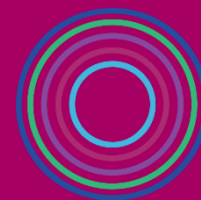




**A GOOD LIFE Has**  
**Rights**  
**&**  
**Responsibilities**



DD Council  
Brochure  
Sample



# Other “Good Life” Branding

- Title of Governor’s Conference and Joining Forces Conferences
- Theme for DD Awareness Day 2015
- New Council State Plan Goal references “Good Lives”
- Youth Leadership Forum theme and iconography used in 2015
- Partners in Policymaking courses revised and expanded with CoP/Good Life tools
- Good Life video  
<https://vimeo.com/87519027>



## Life Categories

Life categories are the different aspects and experiences of life that we all consider as we age and grow, such as daily life, community living, health, and wellness. Everyone (whether you have a disability or not) has to figure out: what you are going to do during the day - go to school, volunteer, get a job; where you are going to live; how you are going to stay healthy and safe; and so on.

- Daily Life**  What a person does as part of everyday life - school, employment, volunteering, communication, routines, and life skills.
  - Community Living**  Where and how someone lives - housing and living options, community access, transportation, home adaptations, and modifications.
  - Healthy Living**  Managing and accessing health care and staying well - medical, mental health, behavior, development, wellness, and nutrition.
  - Safety & Security**  Staying safe and secure - emergencies, well-being, guardianship options, legal rights, and issues.
  - Social and Spirituality**  Building friendships and relationships, leisure activities, personal networks, and faith community.
  - Advocacy & Family Support**  Support for families/individuals - peer support, and self-advocacy.
  - Services & Supports**  Services and supports for individuals and families - both funded (systems) and natural supports; personal/family, and financial.
- Icons courtesy of [Mission: Family in Family](#)



# Evaluation and Data

Discussing postage-paid postcards with evaluation data for the publications.





# Tennessee

**Emma Shouse, Director of Communications**  
TN Council on Developmental Disabilities



# Reframing our Team's Conversations

- New focus on families/individuals not currently served through the service system (i.e., the “100%”)
- Emphasis on value of peer to peer supports
- How to help families access and develop natural supports, community resources



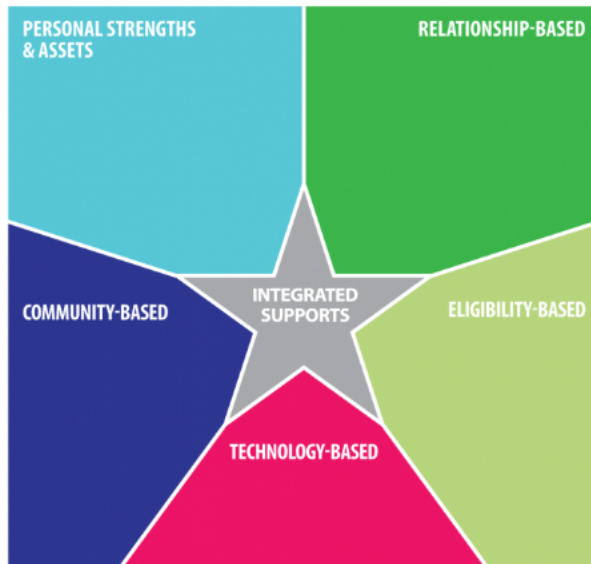


## Supporting Tennessee Families of Individuals with Intellectual & Developmental Disabilities

### A Constellation of Supports

One tool that has been shared among the states participating in the Supporting Families Community of Practice is a graphic called the "Supports Star". The "star" is a way to help individuals and families think about the variety of services and supports that can assist someone in planning for a good life full of meaningful roles, relationships and activities.

Too often, we only talk to families about the assistance that comes through an official service system. But what other opportunities for support for an individual and a family experiencing disability might there be?



This tool is meant to help individuals and families have conversations about resources,

# Supporting Families E-news

Goal: easy and accessible way to communicate with and learn from families

Primary audience – families and individuals with disabilities

Secondary audience – advocates/professionals in the disability field, state agency partners

Already using email marketing tool (MailChimp) for Council news updates – launched new Supporting Families monthly newsletter in Spring 2014





# Supporting Families E-news

## Topics

Life stages and questions to support planning

Life “domains” and questions to support planning

Peer to peer support programs

Community integration, involvement, accessibility

Information and training supports for families

Natural supports

Family success stories

Sibling supports

Value of family and self-advocate voices in policy and planning

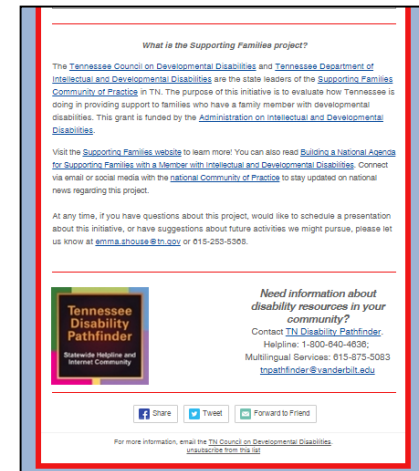
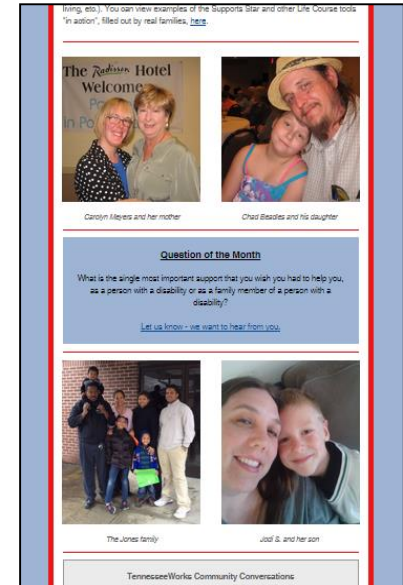


# Supporting Families E-News

## Strategic Communication

Staying consistent:

1. Simple explanation of core concept of Lifecourse framework
2. Related question for families
3. Featured family photos
4. Update on TN team activities
5. Footer with summary of Supporting Families initiative, contact info for TN Disability Pathfinder (I&R office)



# Supporting Families E-news

## Measuring Outreach

- 1<sup>st</sup> Supporting Families e-news: 428 subscribers
- This month's SF e-news (#17): 684 subscribers
- Average of 400-600 total opens per e-news sent (data shows people share within their own networks)
- Tracking responses to questions we ask in e-news, sharing with team to inform our priorities

## Tennessee Kindred Stories of Disability

A collection of stories from individuals with disabilities, families, friends, and disability service providers in Tennessee

“ Mr. Williams credits GOD for his talent and gives thanks to this mother for opening his heart toward art. ”

story: Michael W (49), Blind, Shelby County

[Read Story](#)

This site is currently sharing 118 stories about people with disabilities from 29 Tennessee counties. Do you have a story to share?

### Browse Story Categories

#### Disabilities

- + ADHD (2)
- + agenesis of the corpus callosum (1)
- + Angelman syndrome (2)
- + Arthropods: Multiple Congenita (1)
- + Asperger Syndrome (3)
- + Autism (11)
- + Bipolar disorder (1)
- + Blind (10)
- + brain injury (1)
- + Celiac Disease (1)
- + Cerebral Palsy (15)
- + CHARGE Syndrome (3)
- + congenital adrenal hyperplasia (1)
- + cystic fibrosis (1)
- + Deaf (2)
- + Developmentally Delayed (3)
- + Diabetes (1)
- + Down syndrome (13)
- + Epilepsy (4)
- + Fetal Alcohol Syndrome (1)
- + Friedrich's Ataxia (1)
- + Hearing Loss (1)
- + Intellectual Disability (15)
- + Learning disabilities (1)
- + Muscular dystrophy (1)
- + Obsessive-compulsive disorder (2)
- + Oppositional defiant disorder (1)
- + Other (15)
- + Pervasive Developmental

#### Topics

- + Accessibility (3)
- + Addiction (1)
- + Adult Services (11)
- + Advocacy (8)
- + Areas of Improvement (2)
- + Behavior Challenges (6)
- + Bullying (1)
- + Communication (1)
- + Community Challenges (6)
- + Early Intervention (4)
- + Education (63)
- + Employment (44)
- + Family (45)
- + Family Support (3)
- + Foster Care (1)
- + Future Concerns (41)
- + Health Care (21)
- + Housing (13)
- + Hyperactivity (1)
- + Inclusion (10)
- + Independence (17)
- + IQ Testing (1)
- + Knowledge and Awareness (9)
- + Multicultural perspective (7)
- + personal care (2)
- + Postsecondary education (13)
- + Quality of Life (24)
- + Religion and Spirituality (11)
- + Research (2)
- + Brigitte (8)
- + Self-Directed Worker Program (2)
- + Services (11)

#### Counties

- + Blount (3)
- + Cannon (1)
- + Cheatham (1)
- + Coffee (1)
- + Cumberland (2)
- + Davidson (45)
- + Dickson (2)
- + Fayette (1)
- + Franklin (1)
- + Gibson (2)
- + Hamilton (1)
- + Hamilton (2)
- + Henry (1)
- + Jefferson (1)
- + Knox (4)
- + Lincoln (1)
- + Loudon (1)
- + Madison (1)
- + Maury (2)
- + Montgomery (4)
- + Putnam (1)
- + Robertson (1)
- + Rutherford (5)
- + Shelby (16)
- + Smith (1)
- + Sumner (2)
- + Weakley (1)
- + Williamson (11)
- + Wilson (3)

#### Age

- + 0 to 35 months (4)
- + 14 to 21 years (22)
- + 22 to 35 years (20)
- + 3 to 5 years (12)
- + 36 to 59 years (23)
- + 6 to 13 years (24)
- + 60+ years (4)

#### Perspectives

- + Aunt (1)
- + Friend (1)
- + House Manager (1)
- + Parent (45)
- + Relative (2)
- + Self-advocate (15)
- + Sibling (3)
- + Student interview of parent (47)
- + Student interview of self-advocate (15)

# Kindred Stories Collection

Partnered with University Center for Excellence in Developmental Disabilities

Vanderbilt students interviewed 15 families as part of their coursework

Interviews focused on discovering info about families' use of and access to formal systems of support and informal community supports

Diversity in disability, ethnicity, geography

# Kindred Stories Collection

## Goals for the project:

Compile story collection (Jan. 2016)

*Print and online*

*Include “recommendations for families” - use as practical tool too*

## Disseminate widely

*Sharing stories – helps illustrate successes, challenges and educate families how others are “making it work” with formal and/or informal supports*

*Inform policymakers about families’ needs*

## Research

*UCEDD using data gathered in interviews for research about how families find and create informal supports*

# Other ways we're "reframing"

- Website
- Lunch and Learn events
- Council 5-year State Plan Survey

The screenshot shows the website's navigation menu at the top with options: About Us, Training and News, Projects and Initiatives, Public Policy, and Need Services?. The main heading is "Prenatal/Infancy". A sidebar on the left lists categories: Prenatal/Infancy Services, Early Childhood, School Age, Transition to Adulthood, Adulthood, and Aging. The main content area is titled "Questions to Consider" and includes a paragraph about the "Charting the Life Course" tool, a list of five questions, and a link to download a booklet. A photograph of a smiling baby is featured on the right side of the text.

**Need Services?**

## Prenatal/Infancy

Questions to Consider

Charting the Life Course is a tool, developed by the [Supporting Families Community of Practice](#) and the University of Missouri Kansas City, to assist you in creating a vision for the future. It is designed to help families think about the questions to ask as you "plot a course" to a full and meaningful life for a family member with a disability. Individuals and families can focus on their current stage of life, but families may also find it useful to look towards the future to start thinking about what they can do or learn now that will help build an inclusive, productive life.

The Supporting Families Community of Practice believes that this "life course approach" helps families realize that even when children are young and as he or she grows into adulthood, their experiences and environment can shape how they will live their life in the future.

Here's just a few questions that the "Life Course approach" encourages families to consider, if they have a child with a disability in the prenatal or infancy stage.

1. Do you have a vision or plan in mind for me when I get older that will support my growth and development now?
2. Are there ways you can structure where I live and other surroundings to give me opportunities to do typical activities that young children do?
3. If I need testing or assessment, will insurance pay for it, or are there other funding sources?
4. Do you know how to connect with other parents?
5. Are you telling loved ones or friends about your concerns for me and my health/development?

For a full list of questions families can consider for this stage of life, download the Charting the Life Course booklet and other "Life Course materials" at <http://supportstofamilies.org/resources/lifecourse-toolkit/>.

The screenshot shows the website's navigation menu at the top with options: About Us, Training and News, Projects and Initiatives, Public Policy, and Need Services?. The main heading is "Transition to Adulthood/Leaving High School Services". A sidebar on the left lists categories: Prenatal/Infancy, Early Childhood, School Age, Transition to Adulthood, Adulthood, and Aging. The main content area is titled "Vocational Rehabilitation" and includes a paragraph about the program, a section for "Transition School to Work Program", and a section for "Department of Intellectual and Developmental Disabilities (DIDD)". A photograph of a smiling woman sitting at a desk is featured on the right side of the text.

**Need Services?**

## Transition to Adulthood/Leaving High School Services

For more information on these services and resources, click on the appropriate link under "Related State Services" at the bottom of the page.

### Vocational Rehabilitation

[Vocational Rehabilitation](#) is a federal and state-funded program that helps individuals with disabilities enter or return to employment. The VR program assists individuals with physical, developmental and/or intellectual disabilities and helps them find a job or career that fits their abilities and interests.

### Transition School to Work Program

The Transition School to Work program provides vocational rehabilitation services to eligible high school students with disabilities who are interested in employment. Eligible students receive individualized transition services from a vocational rehabilitation counselor, including vocational assessment; guidance and counseling; assistive technology evaluations; postsecondary training; community vocational training; and job development and job placement.

### Department of Intellectual and Developmental Disabilities (DIDD)

DIDD is the state agency responsible for providing services and supports to Tennesseans with intellectual and developmental disabilities. Services are provided directly or through contracts with community providers.

A variety of home- and community-based services are provided to those eligible for Medicaid waiver services. The



# Washington

**Ed Holen, Executive Director**

Washington State Developmental Disabilities Council



## Informing Families

Ed Holen

Community of Practice

Washington State

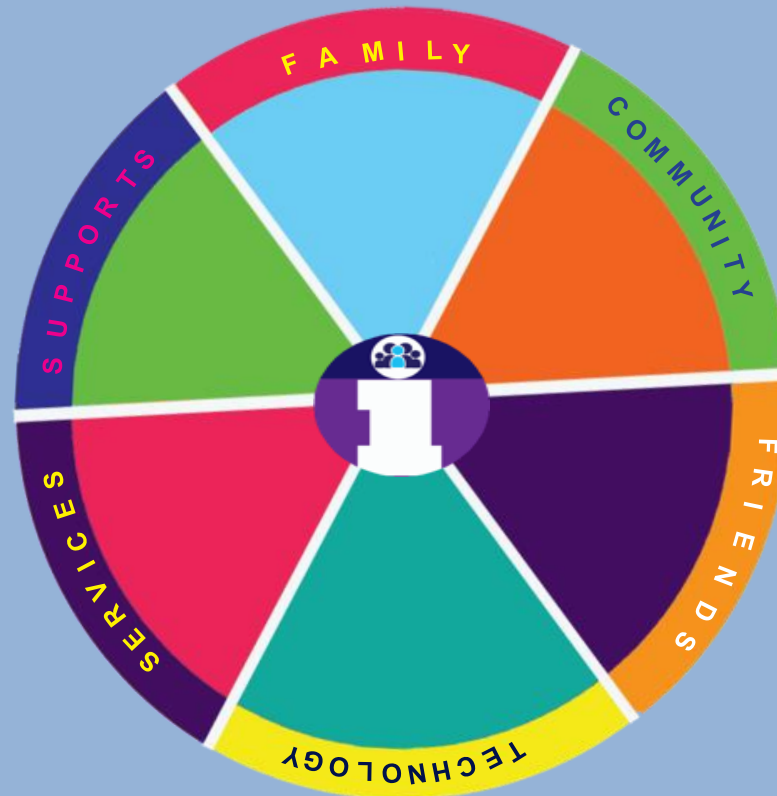
August 27<sup>th</sup> Webinar



# Supporting Real Lives

Across the LifeCourse

**Living** a full life involves so much more than services and systems. It's about **relationships**, community, **natural supports**, and **growing** throughout all **stages of life**.



**Informing Families** provides **trusted** information to help **guide** you and your family member throughout his or her **life**.



**We understand and care about issues that affect children and adults with Intellectual/ Developmental Disabilities.**



**Informing Families is a project of the Washington State Developmental Disabilities Council, in collaboration with the Department of Social & Health Services/Developmental Disabilities Administration.**

**An advisory committee of families and professionals ensures that the information we share is relevant and accurate.**

# Informing Families

*Today and Tomorrow*

JOIN US

Con



nect



Informing Families Online



News & Information



Resources & Support



Services & Systems Planning for the Future

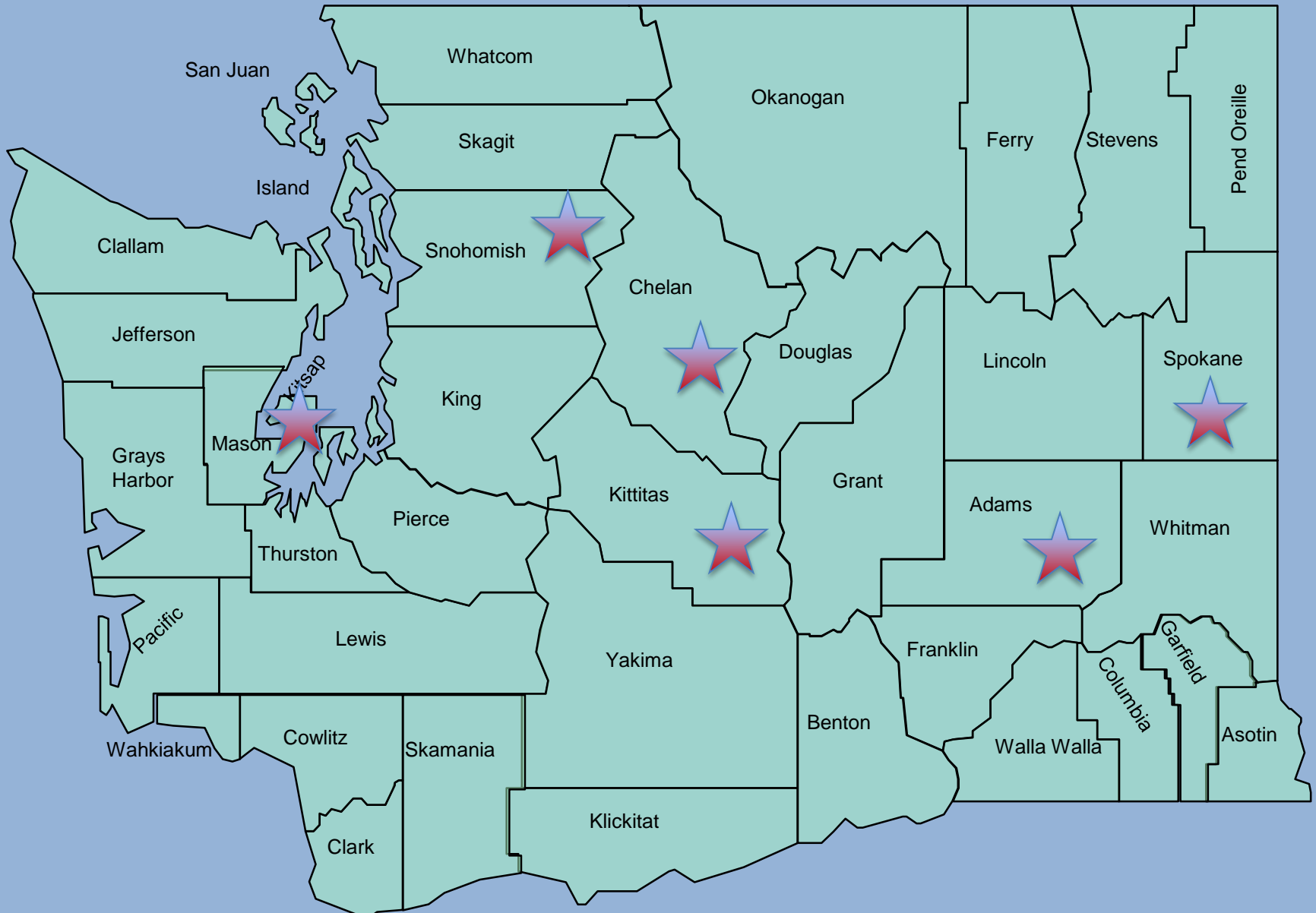
[INFORMINGFAMILIES.ORG](http://INFORMINGFAMILIES.ORG)



NEW

*My Life Plan* is a free online tool to help you and our family member identify interests, strengths and needs at all stages and areas of life. Begin your journey here: [mylifeplan.guide](http://mylifeplan.guide)

# Informing Families Coordinators



# Questions, Reflections and Discussion

# Contact Information

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Ed Holen

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# Innovations Webinar Series

**Next webinar:**

**October 29, 2015**

**Technology & Strategies for Supporting Families**

**Archived webinars:**

- Overview of the LifeCourse Framework
- Focusing on the Front Door of Long Term Services & Supports
- We're All in This Together: Uniting the Movements for a Good Life



# SUPPORTING FAMILIES

of individuals with intellectual & developmental disabilities

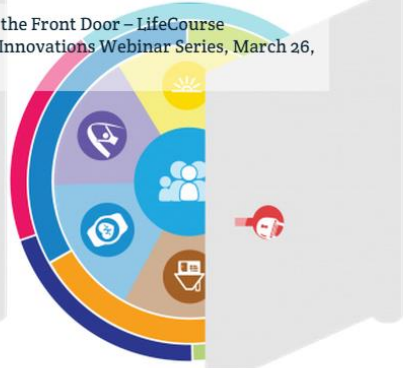

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- Home
- About
- The States
- Resources
- Updates
- Connect

→ Joining Forces TV coverage in Oklahoma! f 📺 📱 📧 📄

### LATESTnews

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

FUNDEDby



ADMINISTRATION ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

NATIONALpartners



### 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\*

- 📄
- f
- 📺
- 📧
- +

Visit us online at [supportstofamilies.org](http://supportstofamilies.org)