

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

**LifeCourse Tools
in Action:
Reaching “the All”
in Tennessee**



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

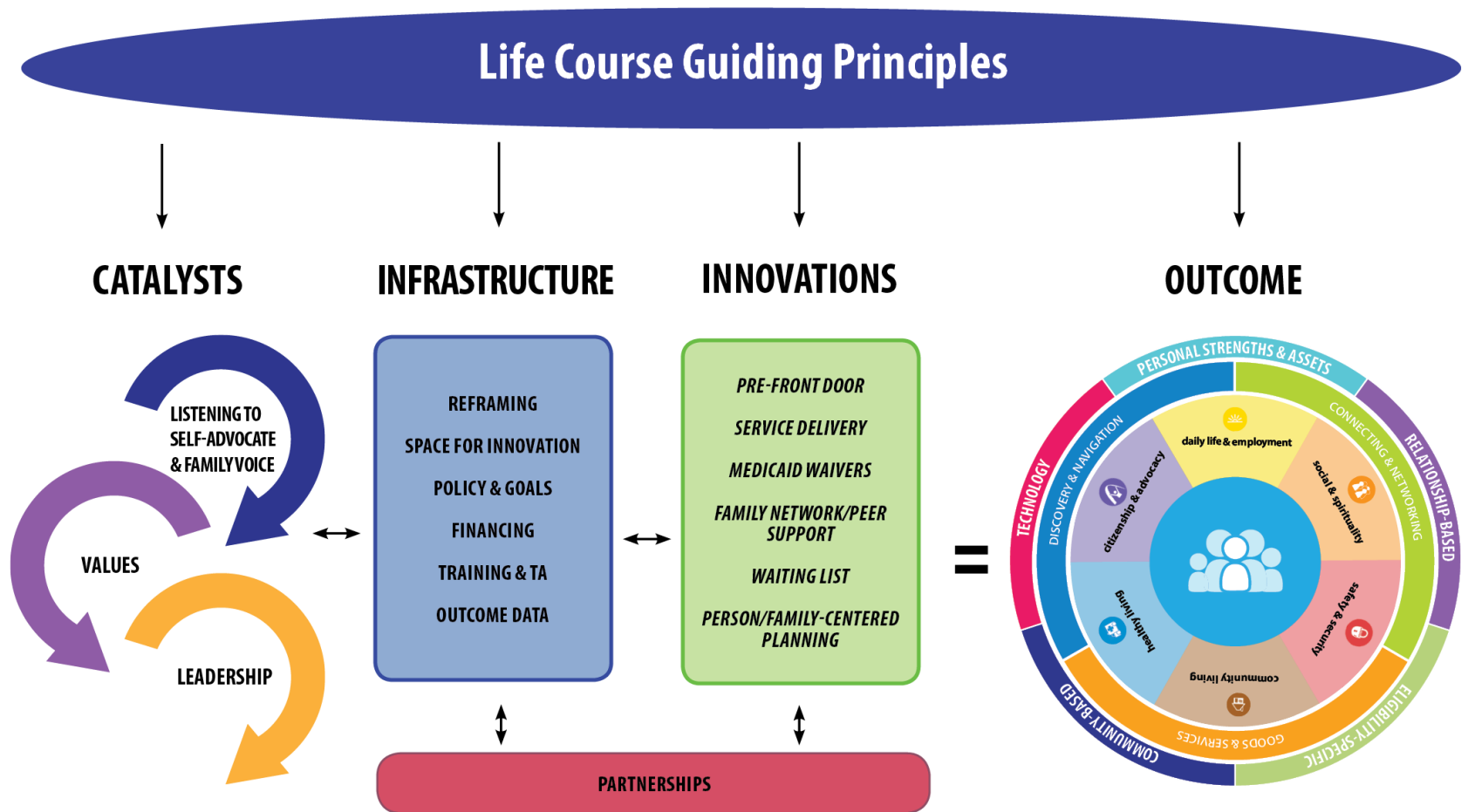
Project Goal

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





The LifeCourse Framework

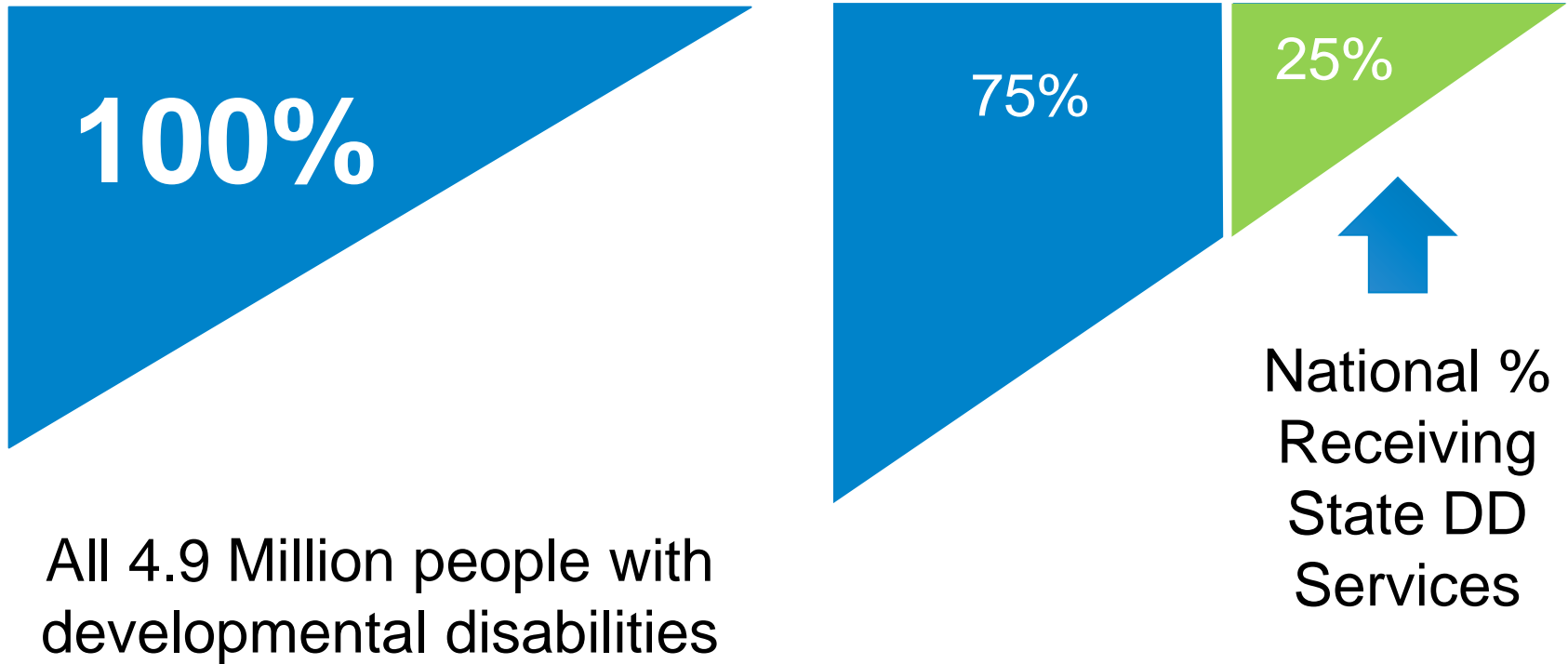
Introduction



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%



LifeCourse Framework



LifeCourse Framework



LifeCourse Framework



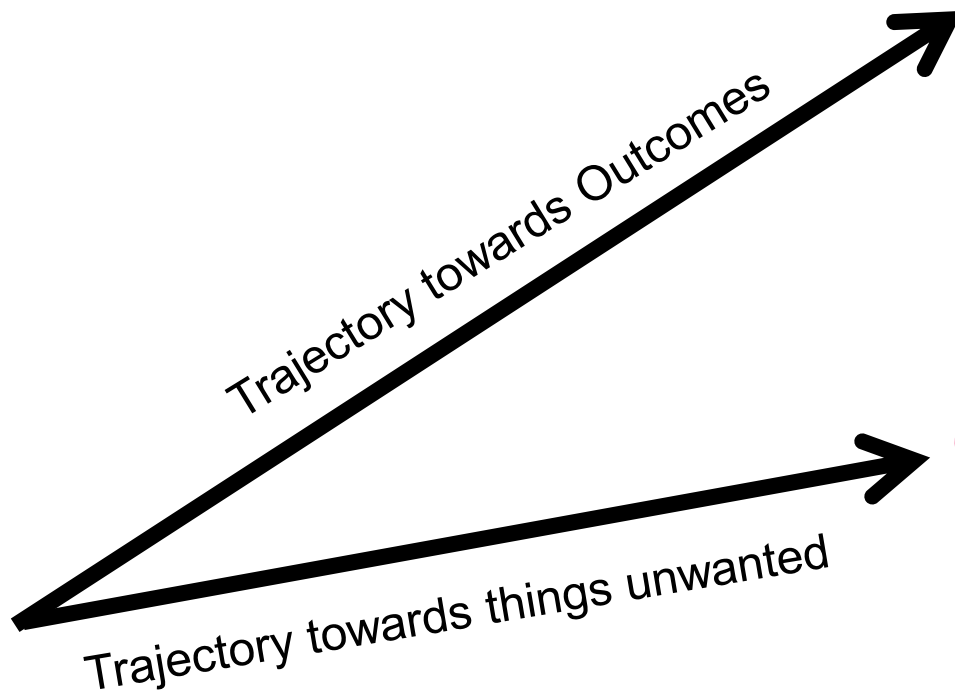
LifeCourse Framework



LifeCourse Framework



Trajectory towards Life Outcomes



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

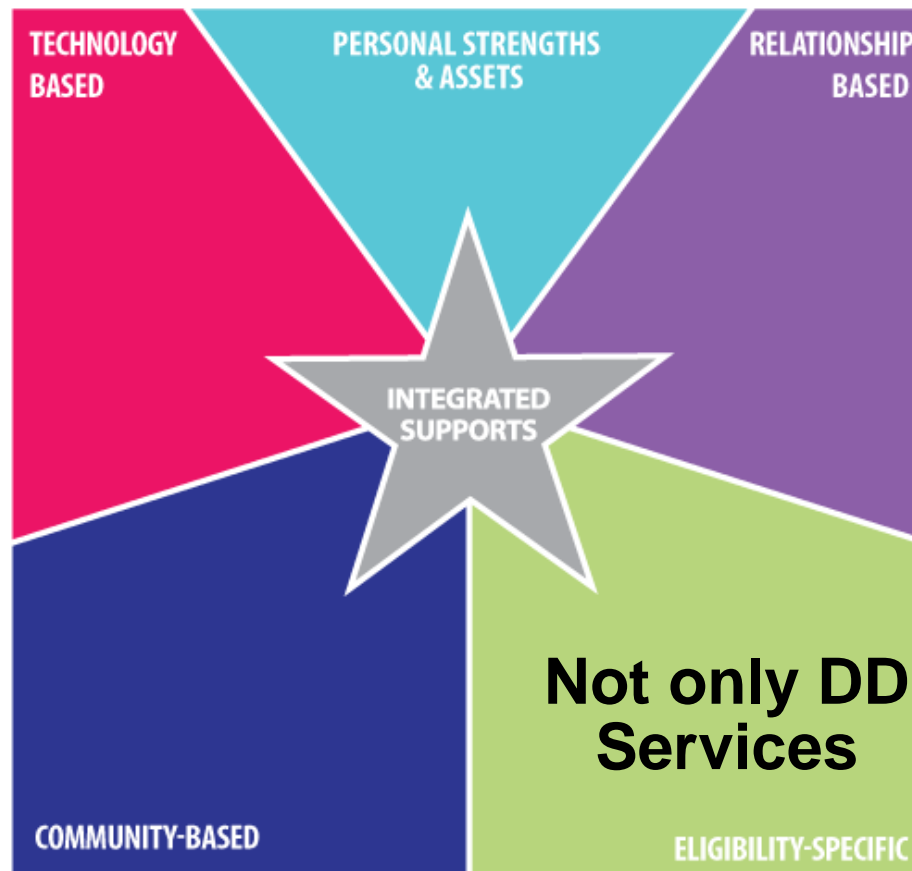
Vision of What I Don't Want



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



Identifying Integrated Strategies for Delivery of Supports



Outcomes for Today's Webinar

1. Understand the principles of the LifeCourse framework,
2. See concrete examples of how the LifeCourse framework and tools are being used by individuals and families as well as professionals to solve problems, troubleshoot life, and plan for the future, and
3. Discover how the LifeCourse is being applied at the organizational, community, and systems level to improve supports to individuals and their families.



COMMUNITY
AND SOCIETY

PUBLIC-PRIVATE
PARTNERSHIPS

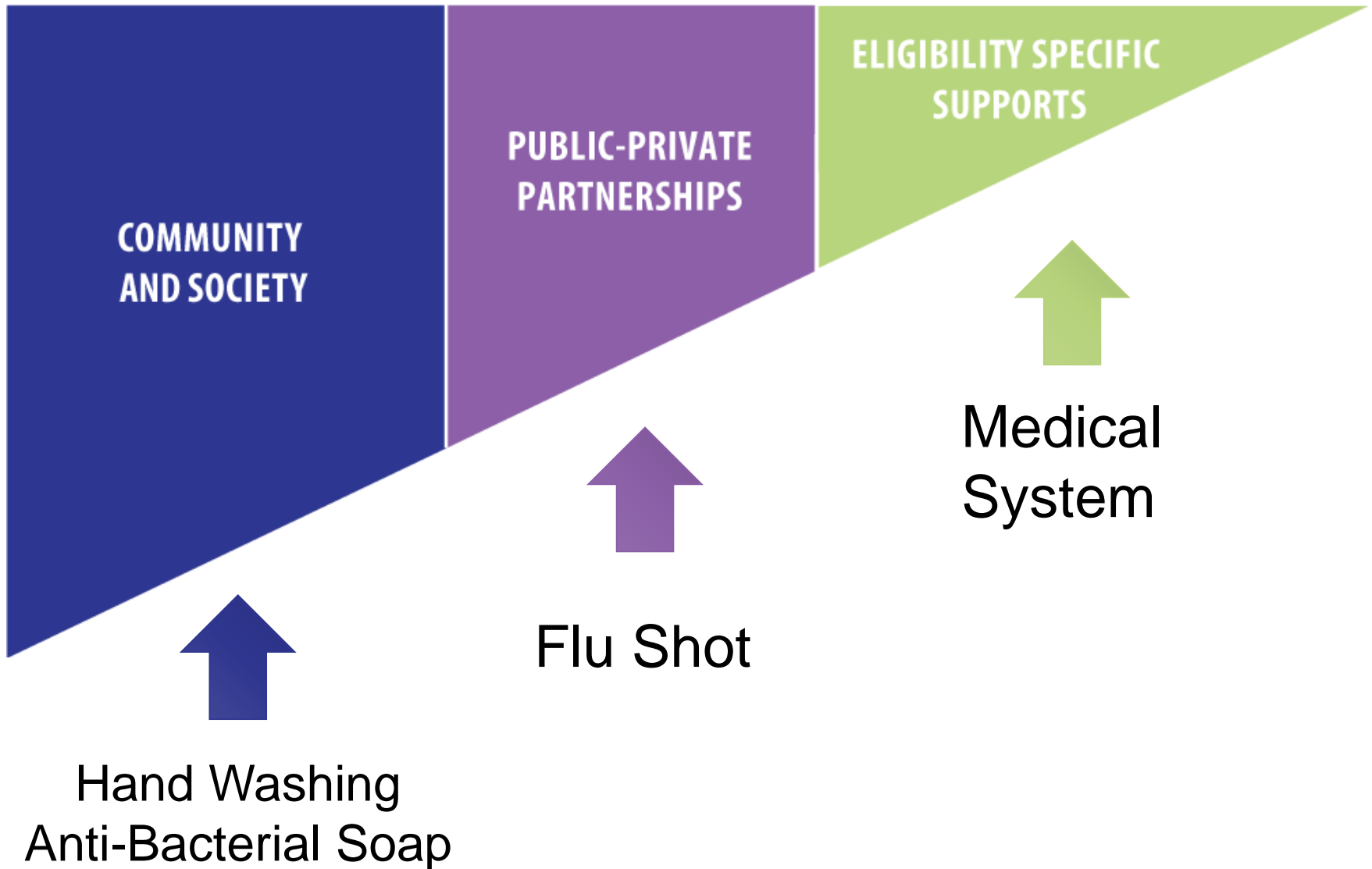
ELIGIBILITY SPECIFIC
SUPPORTS

UNIVERSAL STRATEGY

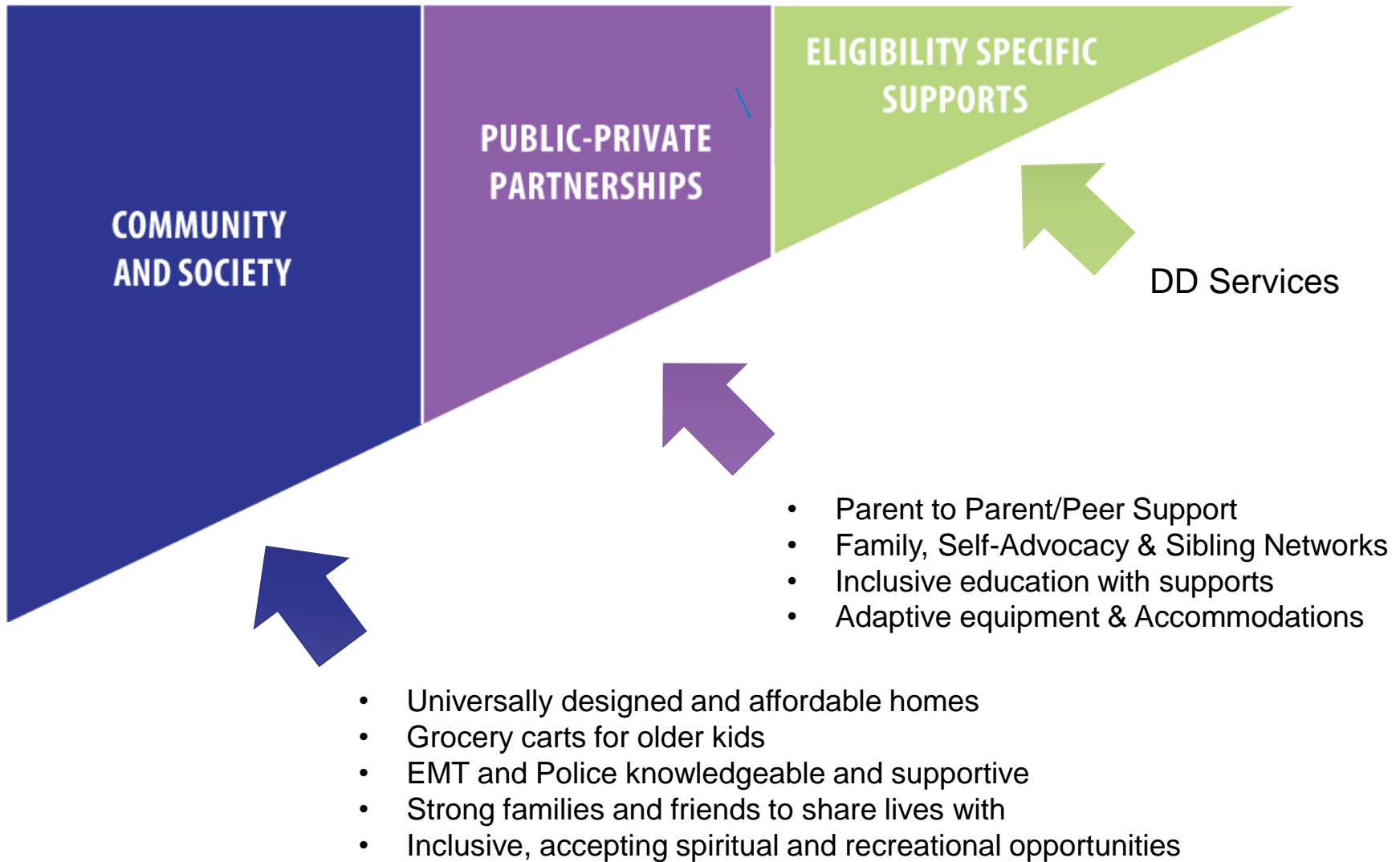
For Providing Supports to Families

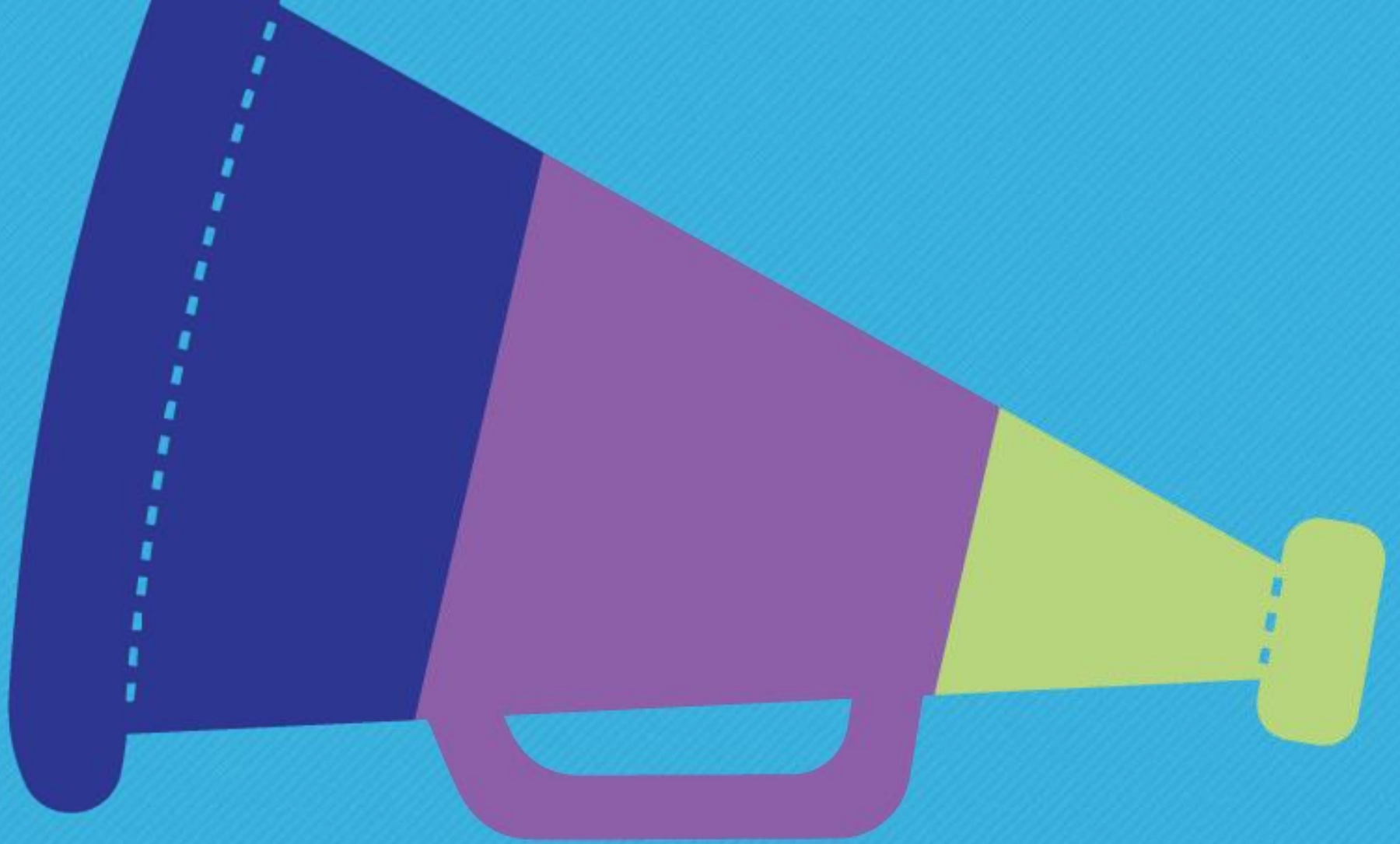


ALL: Public Health Framework



Universal Strategies for Supporting Good Lives for ALL

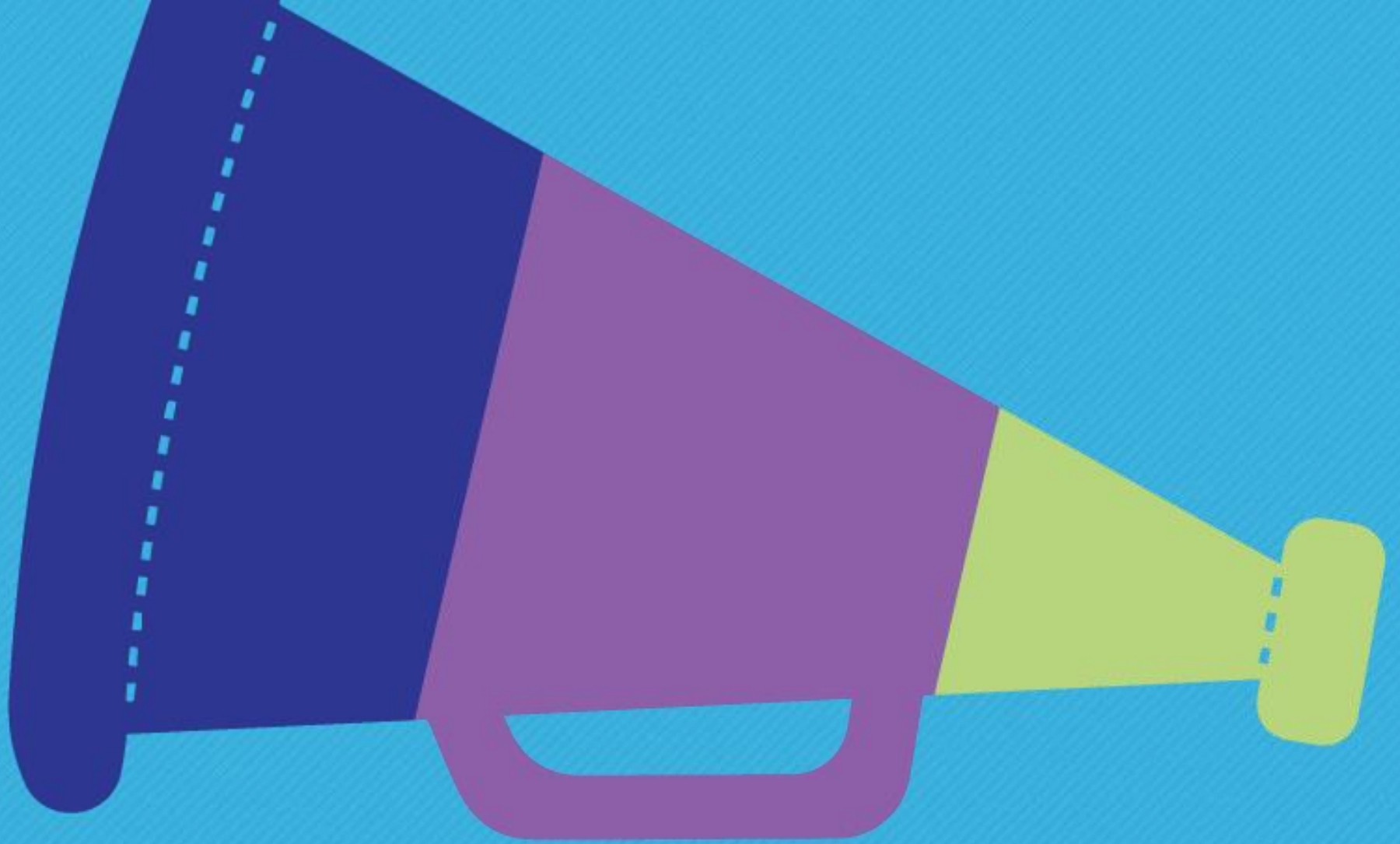




LIFECOURSE TOOLS IN ACTION

Reaching “the All” in Tennessee





COMMUNITY & SOCIETY

Tennessee Developmental Disabilities Council



Benefit of Council Role

- Key role of Councils – create structural change with long-term impact
- Statewide reach
- Disability across the lifespan
- Involving individuals and families in policy
- Located in state government but independent of disability service system
- Building public/private partnerships is part of all our work



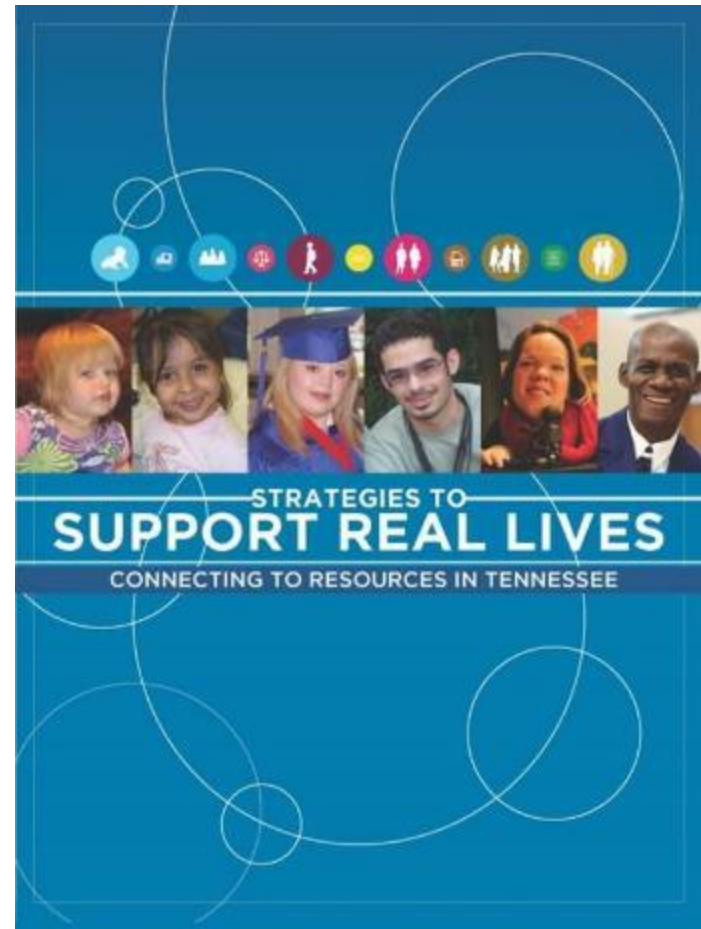
Expanding Outreach to “the 100%”

- University Extension
- Resource folder distribution
- Training Family agents in every county
- Partners in Policymaking



Resource Folder

- Purpose:
 - Assist families in navigating maze of services
 - Promote awareness of informational and emotional supports
- Covers all life domains (health, education, employment, advocacy, etc.)



Expanding Outreach to “the 100%”

KidCentralTN

Online ‘one-stop shop’ for info for ALL Tennessee families

Led by Gov.’s Children’s Cabinet

Partnering to expand content relevant to families with a member with a disability



Have a Child With a Disability? You Need Support, Too.

Parenthood and raising a family can bring many joys and great memories. At the same time, we all know there are financial and emotional realities that come with any child, including children with disabilities. Caring for children with intellectual or developmental disabilities (i.e., cerebral palsy, autism spectrum disorders, spina bifida, Down syndrome, traumatic brain injury, etc.), or special healthcare needs can be challenging, confusing and stressful at times.

Research shows that parents of children with developmental disabilities experience higher levels of chronic stress, anxiety and depression than parents of children without disabilities. Seeking support for yourself as a parent or caregiver can help maximize your own strength, capability and capacity for caring for your child with a disability.

Many times, when we hear the word “support,” our minds go straight to formal programs or services that are specifically for our family member with the disability. However, families and caregivers also need support to help them in their roles as parents and providers of care. In addition to the services that help with day-to-day needs, individuals with disabilities and their families also need information to help guide their decisions and assist them in finding emotional support sources to provide comfort and assurance that they are not alone.

Parents can find emotional and informational support through connecting with and learning from other parents who have children with disabilities, through organizations that serve families of people with disabilities, and through many other avenues in their local community.

Different types of support might include:

- In-person support groups for parents of children with disabilities
- Parent groups online or via social media
- Peer mentoring, or one-on-one emotional support provided by another parent of a child with a disability
- Respite care
- Building skills to be better prepared for advocating for your child
- Faith communities
- Therapy or counseling

Learn more on how to strategize about the types of support you or your family member

Full Family Support

- Community Targeted Transitional Support Services
- Families First/TANF

More...

Related Services

- Family Planning**
The family planning program provides the following medical services: physical exams, cervical cancer screening (including Pap)
- The Family Center - Nurturing Home**
This program offers a combination of 6 group-based parenting sessions* to children and their caregivers, followed by home visits to help

More



Reaching out to Community Partners that Support Families

- Presented LifeCourse tools to community organizations, asked for feedback
- Discussed their staff's information/training needs, info/training needs for families they serve:
- Answers included ...
 - How families can support independence, self-advocacy
 - Self-care and support for caregivers/families
 - How to develop and nurture high expectations for a family member with a disability



Sharing the LifeCourse Framework

- State Agency Lunch and Learns
- TN Disability MegaConference
- Partners in Education conference
- Tennessee Family Coalitions on employment
- Sharing with Council members, Partners in Policymaking, The Arc TN and others



Supporting Families E-News

- Launched Supporting Families monthly e-newsletter in 2014
- Goal: easy and accessible way to communicate with and learn from families
- Primary audience – families and individuals with disabilities
 - Also advocates and professionals in the disability field, state agency partners
- 23 editions; 800+ subscribers



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

Council Website

- New section organized by life stages
- Links families to resources and supports
- Incorporates questions from the *Charting the LifeCourse: Experiences & Questions* booklet for families



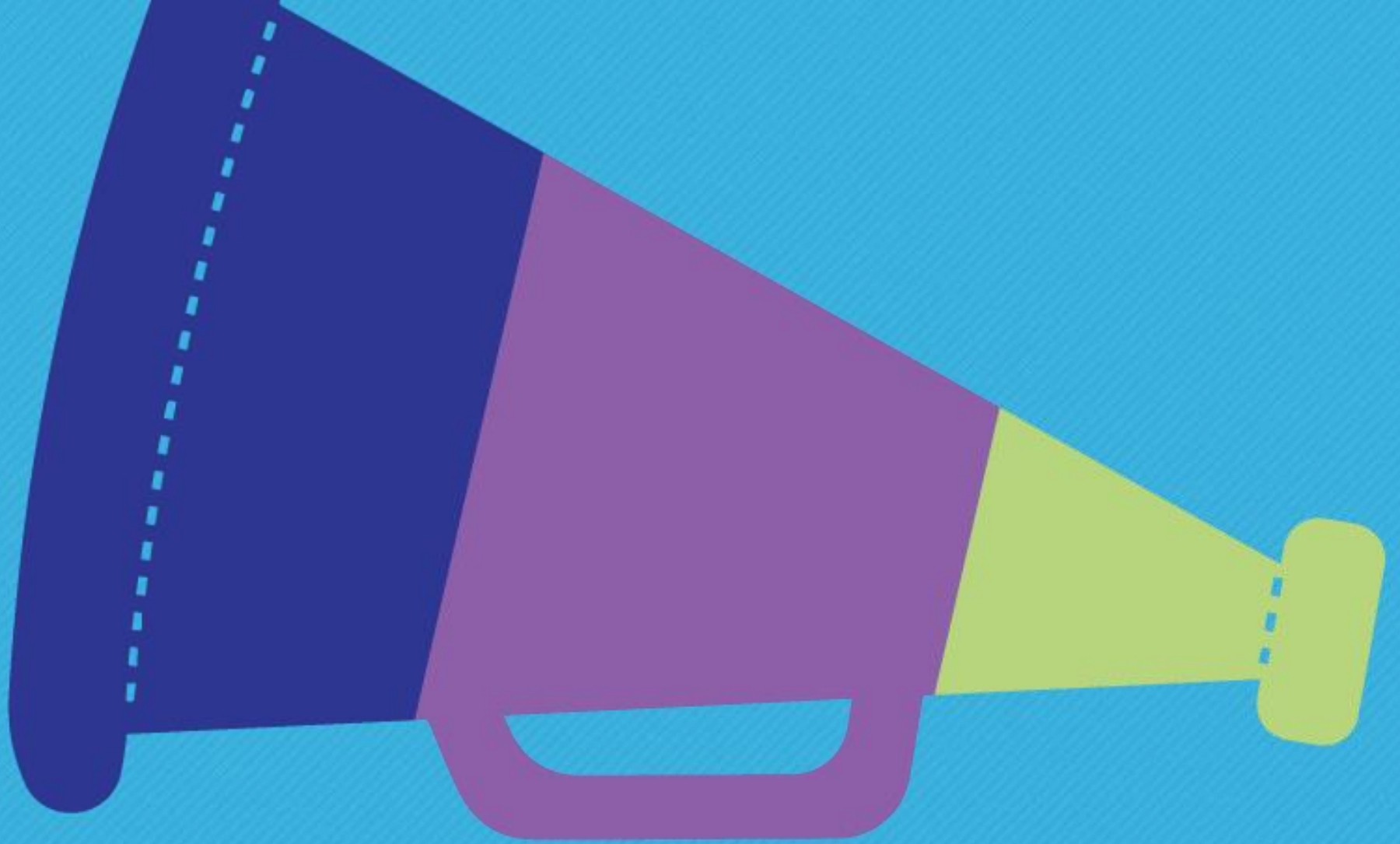
Contact

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PUBLIC-PRIVATE PARTNERSHIPS

The Arc Tennessee



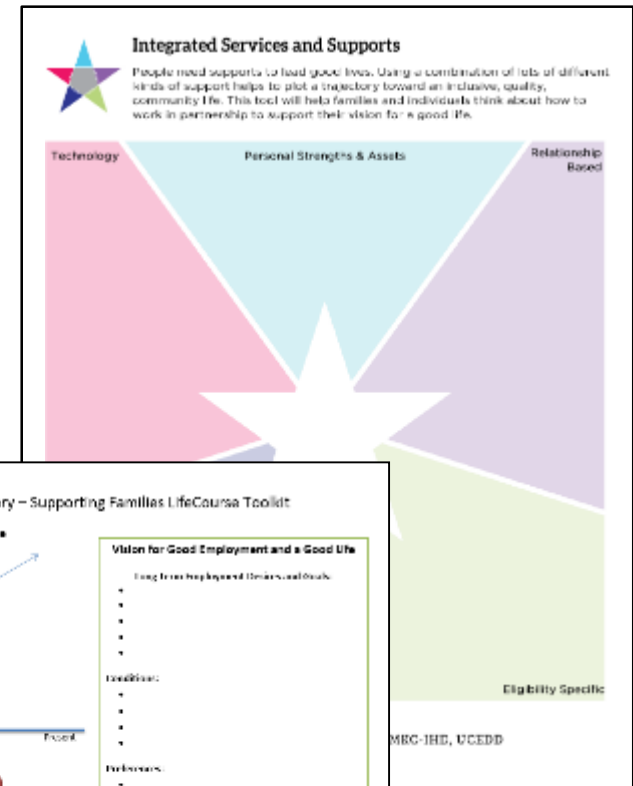
The Arc Tennessee

- Active in the TN Supporting Families Statewide Team since 2013
- The Arc works with many families who are part of the “85%” (don’t have formal supports for their member with a disability)



LifeCourse Framework and Tools

- LifeCourse has been useful for Arc advocates/staff helping families
- Sharing employment LifeCourse tools at TN Family Coalitions, hosted by the Arc



Planning An Employment Trajectory – Supporting Families LifeCourse Toolkit

Contributions: Skills, Talents, Strengths, Experience

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•

Start → End
 (with a line graph showing an upward trajectory from Start to End)

WHAT I DON'T WANT

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Vision for Good Employment and a Good Life

Long Term Employment Objectives:

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Conditions:

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Preferences:

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Support Needs:

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Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities

4044 Arc Ave., Moore's Supporting Families Community of Practice/Center for Supportive Employment by the TN Council on Developmental Disabilities



Connecting Aging, Disability and Supporting Families

- 2015 – Arc TN got grant from Arc U.S. to hold 1-day summit on supporting families of people who are aging/have disabilities
- Shared LifeCourse framework at October summit
- Over 60 disability and aging groups developed strategic plan for supporting families



Strategic Plan for Supporting Families

Strategic plan activities led by the Arc TN; implemented by participants from the summit, Supporting Families team, state agencies, community organizations, etc.

Overall, long-term goal:

Improve supports to all families of people with disabilities and seniors in the state



Strategic Plan for Supporting Families: Goals and Objectives

- Objective: Continue to identify challenges and available resources to support families within both formal and informal systems
- Strategy: Gather information directly from families, individuals with disabilities and seniors on the challenges they face and resources they use
 - *Conduct 2 “Community Conversations” about supporting families in each TN grand region*
 - *Surveying the “85%”*



Strategic Plan for Supporting Families: Goals and Objectives

- Objective: Improve coordination and information sharing to promote supports to families
- Strategy: Create an “alert” system that identifies students with IEPs or 504 plans at age 14, shares with relevant government departments/community organizations
 - *Facilitate conversations around this topic at the Dept. of Education*
 - *Create “universal release of information form” valid across government departments/contracted provider agencies*



Strategic Plan for Supporting Families

Long-range goals of this grant ...

- Continue collaborating with other organizations focused on supporting families in caregiver roles of people with disabilities or who are elderly
- Maximize the use of the LifeCourse tools/framework being shared through the Community of Practice



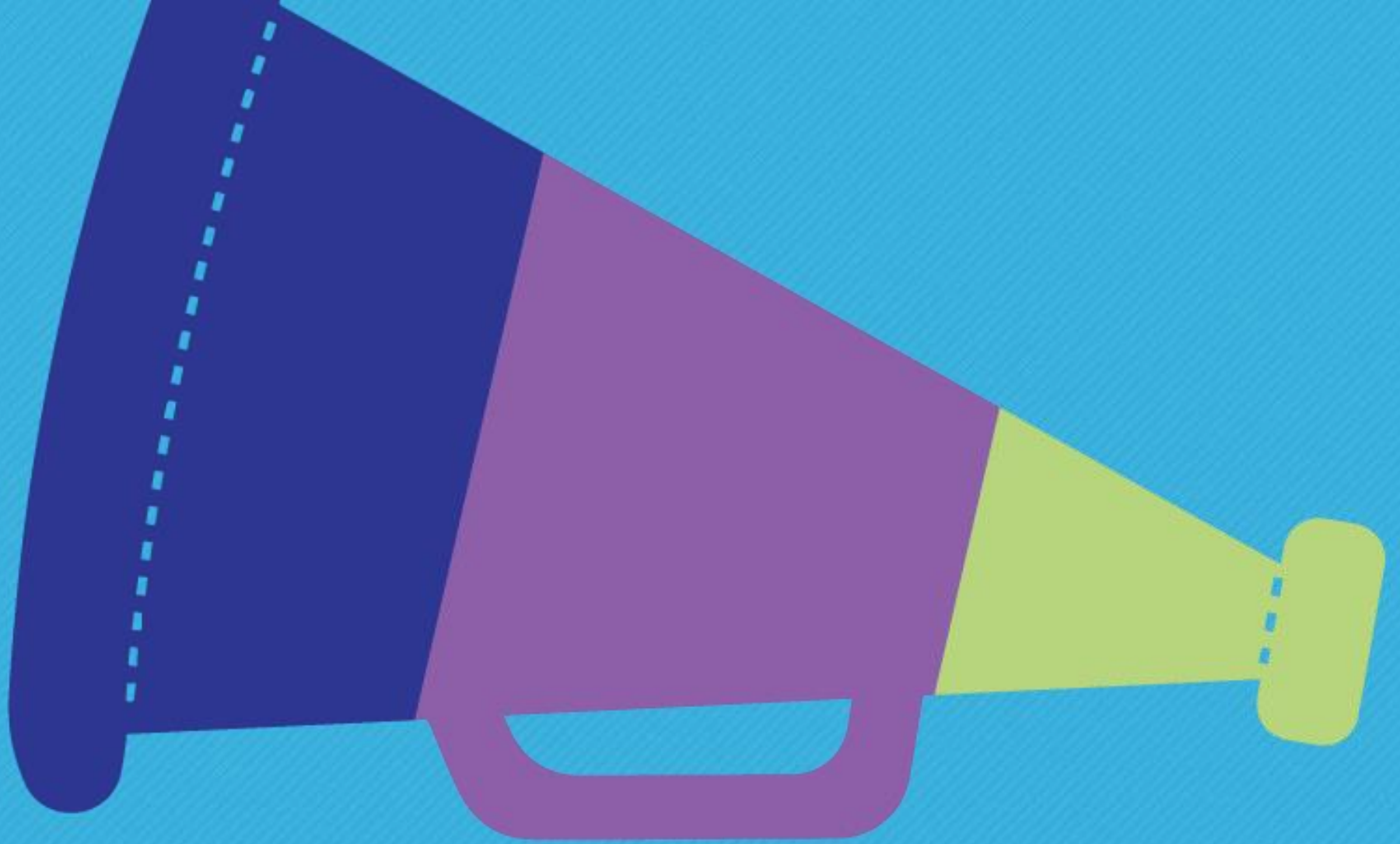
Contact

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ELIGIBILITY-SPECIFIC SUPPORTS

Supporting Families Across the LifeCourse



Developing a Program to Support Families

Employment and Community First CHOICES is a new TennCare LTSS program planned to start on July 1, 2016.

Where did we start?



Developing a Program to Support Families

- Stakeholder meetings began in 2013
- TennCare took the feedback and developed a new “concept”
 - TennCare incorporated public comment, refined the “concept” paper, and created a proposal for a new program.
 - The Centers for Medicare and Medicaid (federal oversight agency for Medicaid programs) approved the program in February 2016



Policy & Systems



Developing a Program to Support Families

Key messages/“themes” from public comment that shaped program:

- Cost-effective programs that could serve more people
- More independent community living options and help engaging in meaningful employment and other activities
- More education on self-empowerment
- Focus on prevention (not waiting for crisis)
- More services for young people exiting high school
- Better coordination between services



Policy & Systems



Developing a Program to Support Families

Create a new program that will:

- Provide the services people and their families say they need most
- Allow us to provide services more cost-effectively
- Serve more people, including people on the waiting list and people with other kinds of developmental disabilities
- Align incentives toward employment, independent living, community integration and the things that people with disabilities and their families value most

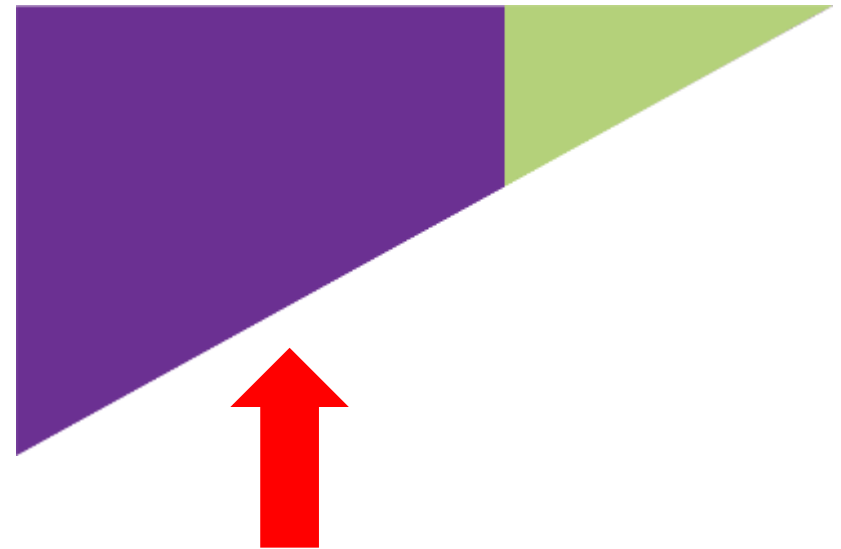


Employment and Community First CHOICES

Who is it for?

- People with intellectual and other developmental disabilities who are not currently receiving services
- Initial enrollment will target groups identified by stakeholders:
 - People with aging caregivers
 - Young adults transitioning from school and other people who need employment supports

People in current waivers are not impacted, but can choose to move to the new program later on



All Individuals & Families:
Approx. 85% do not currently receive services



Employment and Community First CHOICES

What will it offer?

- Benefits that people with I/DD and their families say they need most
- Support for families caring for a person with I/DD
- Supports to help people with I/DD achieve employment and independent living goals
- For people who choose not to work or need more support to live in the community - residential and other day services to help them achieve their community living goals
- Includes consumer direction options



Supports offered through the ECF waiver

Three benefit groups:

- Essential Family Supports
- Essential Supports for Employment and Independent Living
- Comprehensive Supports for Employment and Community Living



A few examples of the
services available...



Employment-Focused Supports

A full spectrum of Employment Services to help you...

- *Decide if you want to work and the kinds of jobs you might like and be really good at.*
- *Try out certain jobs to see what they're like and what you need to do to get ready for those jobs.*
- *Write a plan to get a job (or start your own business) and carry out that plan.*
- *Have a job coach to support you when you start your job until you can do the job by yourself or with help from co-workers.*
- *Get a better job, earning more money.*
- *Understand how the money you earn from working will impact other benefits you receive, including Social Security and TennCare.*



Family-Focused Supports

- Family Caregiver Education and Training
- Family to Family Support
- Family Caregiver Stipend
- Respite
- ...and more!



Self-Advocacy Supports

- Individual Education and Training
- Family Caregiver Education and Training
- Conservatorship and Alternatives to Conservatorship Counseling and Assistance
- Health Insurance Counseling/Forms Assistance (TDCI)
- Peer-to-Peer Self-Direction, Employment and Community Support and Navigation
- Community Support Development, Organization and Navigation
- ...And more!





Program Design



Program Design



The new program will be different from the current waivers because it will be operated by TennCare health plans (“Managed Care Organizations” or “MCOs”).

- *Managed Care helps us achieve one of the things stakeholders recommended: making sure HCBS are coordinated with other needs, like medical and behavioral services.*
- *It also helps us align incentives (like payment for services) in ways that help people achieve their goals.*



Program Design



- Everyone receiving services will have a “Support Coordinator” who develops a Person-Centered Support Plan.
- TennCare is working in partnership with our I/DD Department and our Developmental Disabilities Council to make sure health plans are equipped for person-centered planning.





The Role of Family Caregivers

Role of Family Caregivers



Critical importance recognized in the TennCare/MCO contract; MCOs must assess the needs of family caregivers, including an annual assessment of the needs of family caregivers;

The Caregiver Assessments results in:

- *A plan to address the needs of each caregiver to maintain the health and well-being of each caregiver and sustain their ability to provide care to the member*
- And, included as part of the plan of care is:
“Caregiver training or supports identified through the caregiver assessment that are needed to support and sustain the caregiver’s ability to provide care for the member”





To summarize...



ECF CHOICES is designed to:

- Help families stay together and stay strong (prevent crisis)
- Help children and youth with intellectual and developmental disabilities **believe** they can graduate from high school, get a job, and live independently in the community **and** offer them the support they need to **achieve** it
- Help people have the best possible health and quality of life—to live the lives *they* want to live in the community

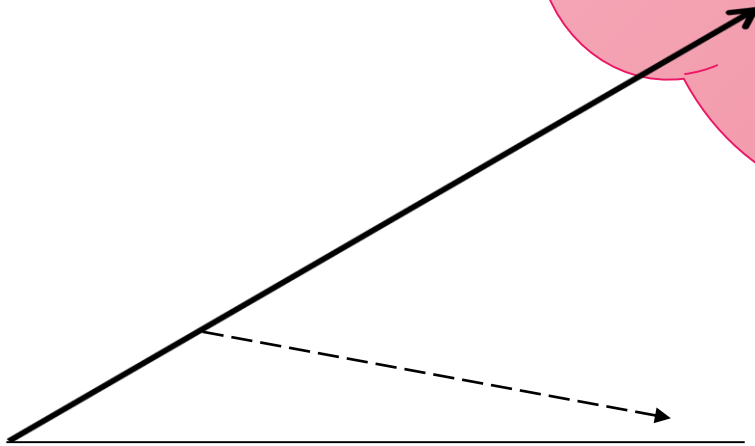


Each Person in ECF CHOICES

Will be supported to make and reach their own goals in areas like:

A full life in his or her community including:

- A job that is interesting to the person, pays a competitive wage, and involves work that is important to the community
- A home and home life that the person chooses in the community
- A chance to be involved in activities in the person's community, and to be known and appreciated by others who live in the same community
- A chance to have meaningful relationships with people who care, and are not paid to care
- A chance to be as independent as possible and have the dignity of risk to do and achieve things other people might have thought were not possible



Contact

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TennCare

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Questions, Reflections & Discussion



LIFECOURSE TOOLS

LIFECOURSE TOOLS

LIFECOURSE PRINCIPLES

LIFECOURSE IN ACTION ▾

CONNECT ▾

ABOUT



LifeCourseTools.com



Innovations Webinar Series

Next webinar:

Details coming soon

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
- Reframing the Conversation at All Levels: Tools for Change
- Technology & Strategies for Supporting Families
- LifeCourse in Action: Implementation at all levels in Missouri





SUPPORTING FAMILIES

of individuals with intellectual & developmental disabilities

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LifeCourse Showcase: Missouri LifeCourse Tools & Practice Workgroup post

LATEST news



LifeCourse Tools in Action: Reaching the All in Tennessee CoP Innovations Webinar March 24, 2016

FUNDED by



ADMINISTRATION ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

NATIONAL partners



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 (IDD).

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 State Directors of Developmental Disabilities Services (NASDDDS).

MAILINGlist

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

First Name

Last Name

Visit us online at supportstofamilies.org