

THE
NATIONAL
COMMUNITY
OF PRACTICE



Setting the Stage

History of Family Support and the CoP

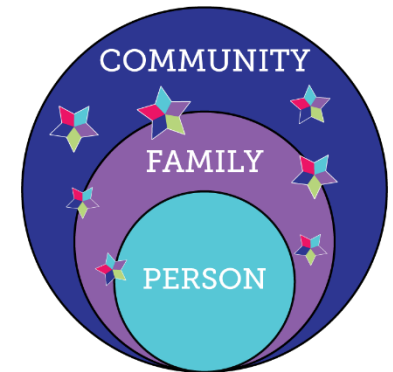
Building on History of Supports

1950s Self-Advocacy and Family Movements

1960s Medicaid & Medicare
1980s Medicaid Waiver

1970s Rehab & Education Act
1990s IDEA and ADA

2000's Inclusive Community

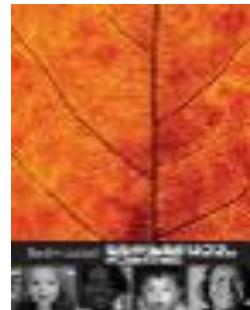


Moving to Supporting Families

*Wingspread
Conference at
Johnson Foundation
March 6-8, 2011
Racine, Wisconsin*

*ACL funded AUCD
Family Support SIG*

*Building an agenda
for supporting families
with a member with
intellectual and
developmental
disabilities*



Goal of Supporting Families

Person

Each member of the family will be supported to achieve self-determination, productivity, integration, inclusion in all facets of community life

Family Unit

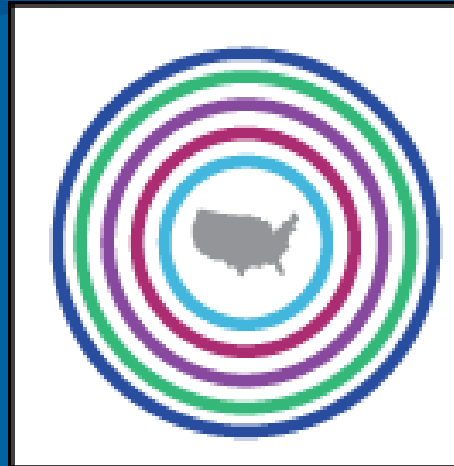
Families will be supported in ways that maximize their capacity, strengths and unique abilities to best nurture, love, and support individual members to achieve their personal goals

Recognizes Needs of Family Unit

**DISCOVERY
AND
NAVIGATION**
Knowledge &
Skills

**CONNECTING
AND
NETWORKING**
Mental Health
& Self-Efficacy

**GOODS
AND
SERVICES**
Day-to-Day
& Caregiving
Supports



National Community of Practice on Supporting Families

Original Grant: 2012-2016



National CoP for Supporting Families

National Association
of State Directors of
Developmental
Disability Services

NASDDDS

University of Missouri
Kansas City, Institute
for Human
Development, UCEDD



Evaluator: Human Services Research Institute

CoP 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 that include a member with I/DD across the lifespan.

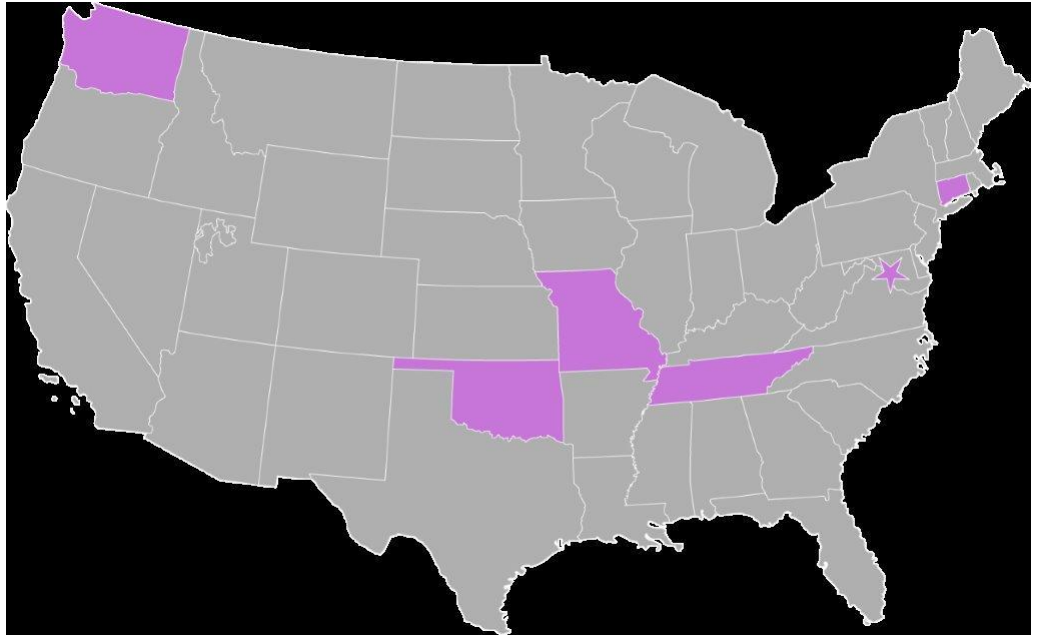
What is a Community of Practice?

Communities of practice are groups of people who share a passion for something that they know how to do and who interact regularly to learn how to do it better.

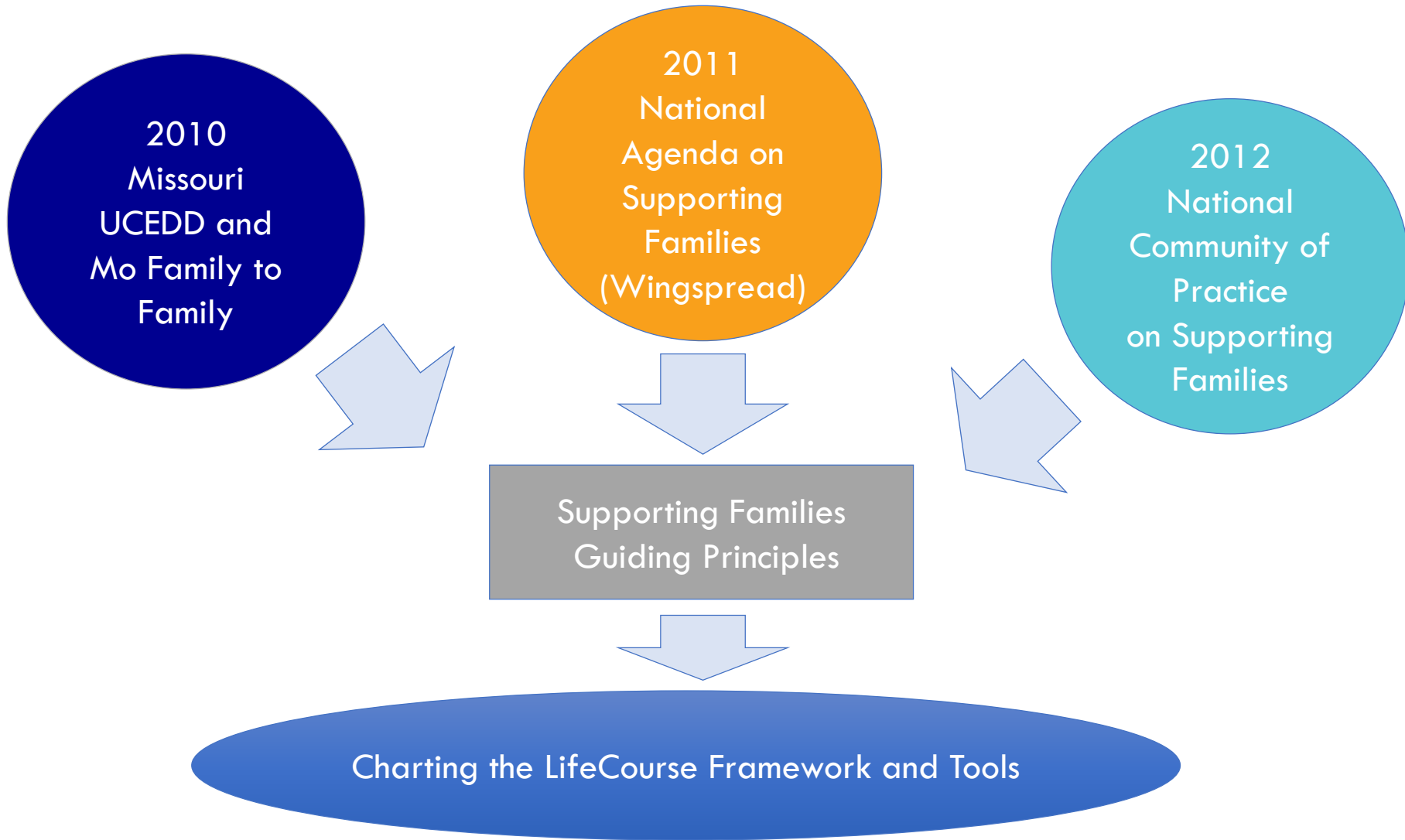
Blue Space.....intentional space to create innovation that is safe amongst chaos and destruction
(Creating Blue Space, Hanns Meissner)

Original CoP States

- District of Columbia
- Connecticut
- Oklahoma
- Tennessee
- Washington
- Missouri (Mentor)



Development of National Framework



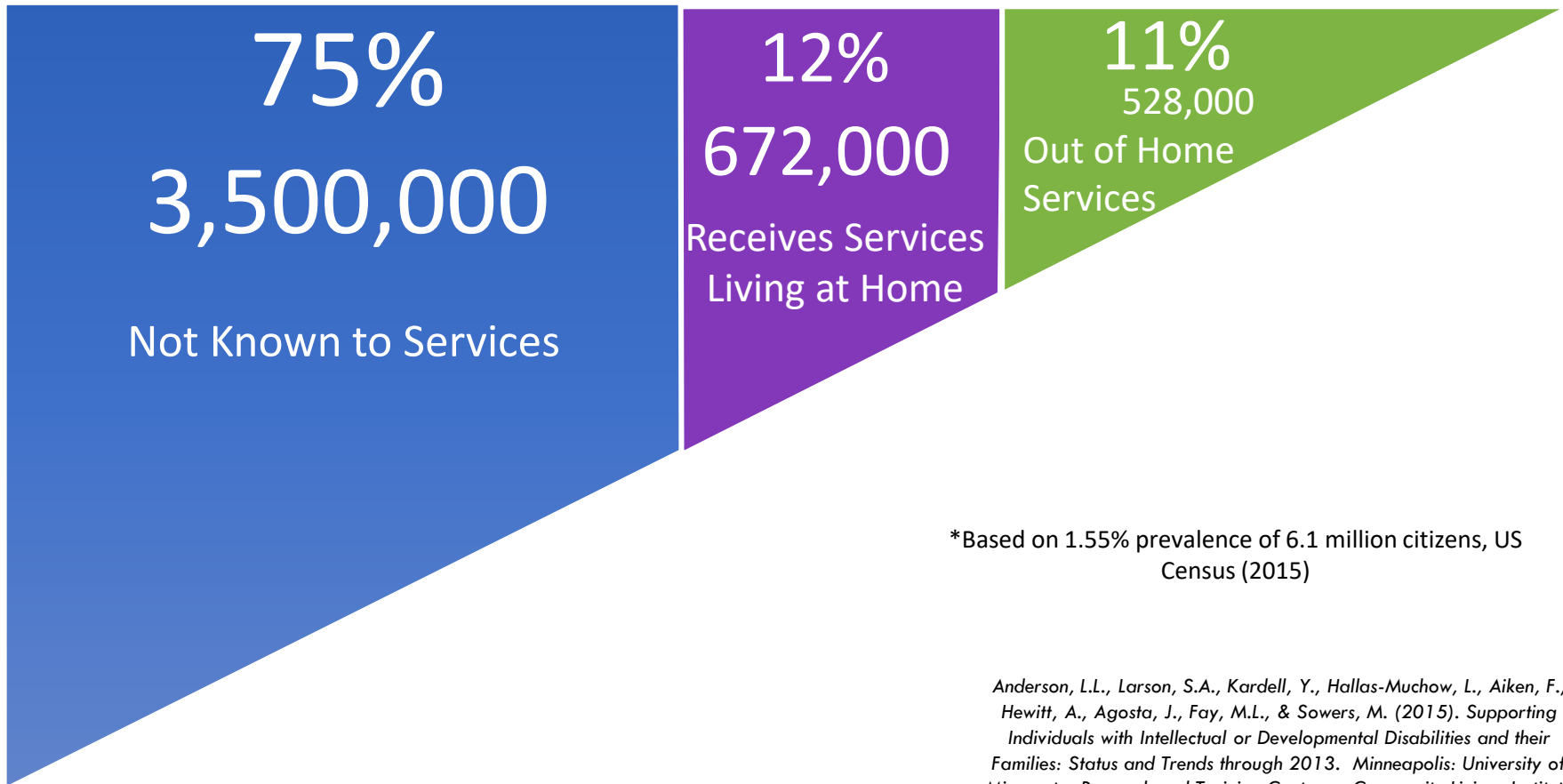


Core Belief:
All people and their families
have the right to
live, love, work, play, (learn),
and pursue their life
aspirations.



Focusing on All People with DD

4.7 million estimated People with Developmental Disabilities*



*Based on 1.55% prevalence of 6.1 million citizens, US Census (2015)

Anderson, L.L., Larson, S.A., Kardell, Y., Hallas-Muchow, L., Aiken, F., Hewitt, A., Agosta, J., Fay, M.L., & Sowers, M. (2015). Supporting Individuals with Intellectual or Developmental Disabilities and their Families: Status and Trends through 2013. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

Charting the LifeCourse Framework



*Developed by and for people with disabilities
and their families*

NASDDDS



CoP Phase II and III

Funded by State Membership Fees

Phase 2: Membership CoP

- District of Columbia
- Connecticut
- Oklahoma
- Tennessee
- Washington
- Missouri (Mentor)
- **Alabama**
- **Delaware**
- **Kansas**
- **Hawaii**
- **Indiana**
- **Maryland**
- **Ohio**
- **Oregon**
- **Pennsylvania**
- **South Dakota**

Phase 3: Membership CoP

Integration

- District of Columbia
- Alabama
- Delaware
- Indiana
- Maryland
- South Dakota

Sustainability

- Connecticut
- Oklahoma
- Missouri
- Kansas
- Hawaii
- Ohio
- Oregon
- Pennsylvania

Development

- **New Jersey**
- **Michigan**
- **Massachusetts**
- **Minnesota**
- **Virginia**

Structure of Memberships

Development/Integration

- Annual CoP Meeting
- Facilitator Calls
- Website - state pages
- Innovation Work Groups
- Monthly State TA Calls with National Team
- Ambassador Series (5) with coaching
- Showcase Registration (3)
- Annual Visit (New States)

Sustainability

- Annual CoP Meeting
- Facilitator Calls
- Website - state pages
- Innovation Work Groups
- 4 hours of TA per year

Policy, Practice and Culture Change



CoP Innovations and Impacts

Mary Sowers, NASDDDS

Supporting
Priority
Initiatives to
Enhance Person
and Family
Centered
Supports

- Implementation of the HCBS Final Settings Rule
- Technology First
- Employment First
- Quality Outcome Development and Measurement
- Contracts and RFPs

Areas of
Innovations to
Enhance Person
and Family
Centered
Supports

- Front Door
Individual and
Family
Engagement
- Technology First
- Transition and
Employment
- Peer-to Peer
- Supported
Decision Making

Change in Policies and Services to Enhance Person and Family Centered Supports

- New waivers
- New services
- Legislation
- Revising eligibility
- Change in employment and self-directed programs

Aligning Processes to be Person and Family Centered

- ISPs
- Intake and referral forms and processes
- Hiring and retention processes
- Capacity building processes
- Staffing positions created



*National Community
of Practice for
Supporting Families
Annual Evaluation
Report 2018-2019*

<https://acl.gov/programs/program-evaluations-and-reports>

Partnering with UCEDDs

Panelists

Celia Schloemer

University of Cincinnati

Colleen McLaughlin

Rutgers

Parthy Dinora

Virginia Commonwealth University

Panelists' Perspectives

- Why did your state join the CoP?
- What has been (or will be) the role of your UCEDD?
- What type of activities and outcome are occurring or have occurred?

LifeCourse Nexus



UMKC Institute for Human Development

Charting the LifeCourse Nexus



Exchange

- Access to Resources and Tools
- Training
- Technical Assistance



Build

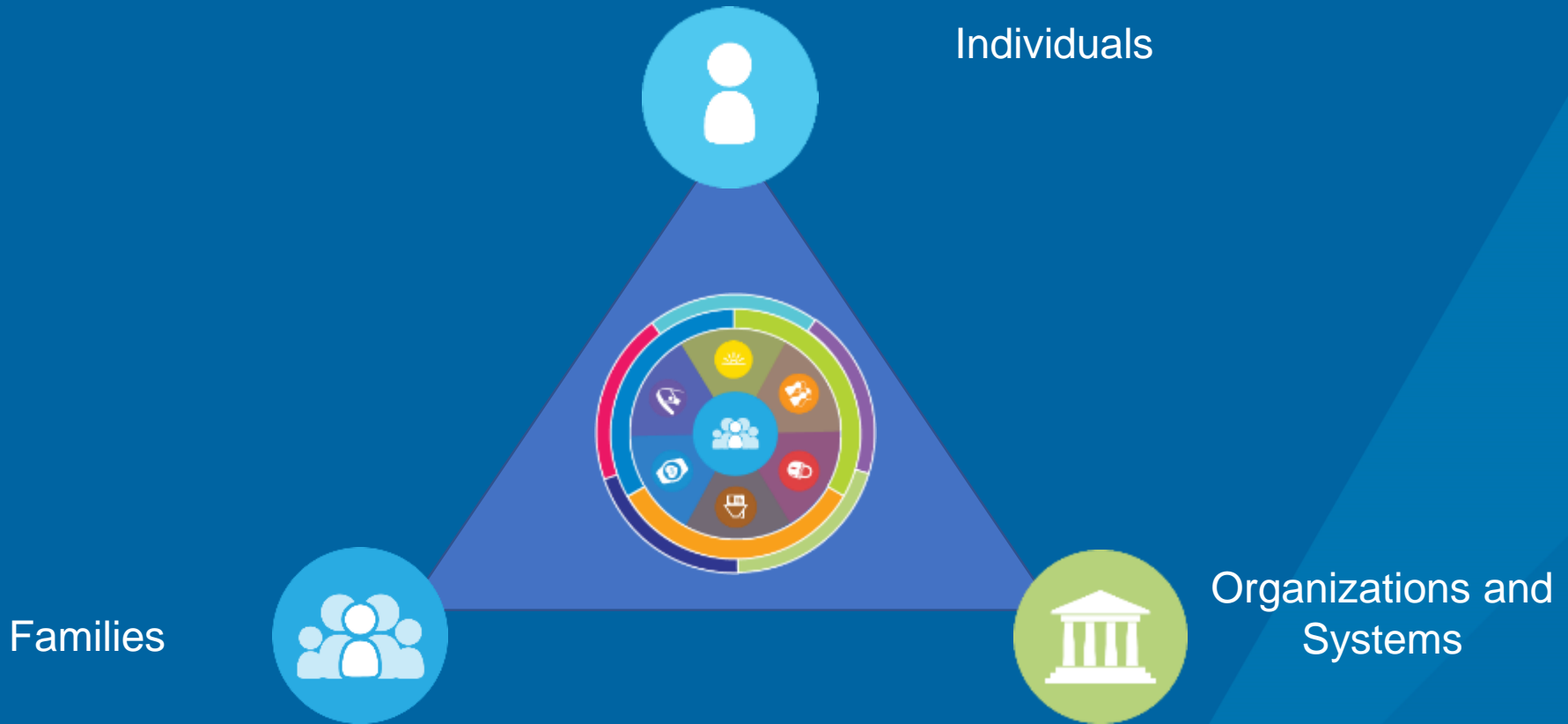
- Innovate and Enhance
- Develop
- Research



Collaborate

- Network and Connect
- Share Learning
- Share Stories

Impacting All Levels



CtLC for Enhancing Self-Advocate and Family Leadership

- Partners in Policy Making (DDCs)
- LEND Family Discipline Faculty
- MO Family to Family Resource Center

Developing Resources for Families and Self-Advocates

- MO DDC Victimization Prevention Grant
- WITH Foundation Healthcare Supported Decision Making Toolkit
- ACL Supported Decision Making Grant
- DDRP NDI Financial Literacy and Community Participation

CtLC for Organizational Change

- Direct Service Providers
- Targeted Case Managers
- IT Systems/Electronic Health Records
- Managed Care Organizations

CtLC for System Transformation LTSS for People with IDD

- Indiana Waiver Redesign (HSRI)
- Living Well Grant (ACL)
- Missouri Support Coordination Enhancement

CtLC for Transformation in Other and Across Systems

- National Center for Advancing Person Centered Practices and Systems (HSRI)
- Lewin No Wrong Door Business Case
- CT Educational System
- OR Aging and Physical Disability



Bringing All Stakeholders Together



4th Annual Charting the LifeCourse

SHOWCASE 2020

APRIL 29-30, 2020 | KCMO



UMKC Institute for
Human Development
Charting the LifeCourse Nexus

The intersect of ideas, collaboration and transformation.
www.LIFECOURSETOOLS.com