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 intellectual and developmental disability across the lifespan.
Project Outcomes

• State and national consensus on a national framework and agenda for improving support for families with members with I/DD.
• Enhanced national and state policies, practices, and sustainable systems that result in improved supports to families.
• Enhanced capacity of states to replicate and sustain exemplary practices to support families and systems.
Setting the Stage
Services and Supports are Evolving

Everyone exists within the context of family and community

Traditional Disability Services

Integrated Services and Supports within context of person, family and community
Type of 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
GUIDING PRINCIPLES FOR THE SUPPORTING FAMILIES LIFECOURSE FRAMEWORK
Partnering with People with Disabilities and their Families so they can Engage, Lead, and Drive Policy and Systems Change
Comprehensive, Integrated & Coordinated Systems Across Life Domains & Stages

- Pediatrician, Families and Friends, Faith based
- IDEA Part C, Parents as Teachers, Health, Headstart
- School, Special Education, Health, Recreation
- Vocational Rehab, Health Employment, College, Military
- Disability Services, Health, Housing, College, Careers
- Retirement, Aging System, Health
Core Belief:
All people and their families have the right to live, love, work, play and pursue their life aspirations in their community.
“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.
1 in 4 Persons with I/DD Receive Formal State DD Services

100%
4.7 Million people with developmental disabilities

75%
25%
National % Receiving State DD Services

**Based on national definition of developmental disability with a prevalence rate of 1.58%**
Ohioans with Disabilities

183,188 estimated Ohioans with Developmental Disabilities

49% (89,737)

29%

20%

2%

Based on 1.58% prevalence of 3.815 million citizens, US Census
Family Life Experience Impacts Trajectory

Biology: Likes, dislikes, skills, abilities

Policy: Dreams, aspirations, house rules, cultural rules, expectations

Environment: Neighborhood, socio-economic, education

Social: Family and friend network, connection with community members

Family Unit Impacts Individual Level Characteristics

Family Cycle Impacts Member Life Cycle

Family Lifelong Impact on Members
Trajectory towards Life Outcomes

Focusing on Past, Present and Future Life Experiences

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

Vision of What I Don’t Want

• Adapted from “Life Course Theory” and Rethinking MCH: The Life Course Model as an Organizing Framework, HRSA, Maternal and Child Health Bureau
Families Need Assistance in Identifying, Developing and Integrating Supports & Services

**Technology Based**
- i-pad/smart phone apps, remote monitoring, cognitive accessibility, adaptive equipment

**Personal Strengths & Assets**
- person or family resources, abilities, strengths, characteristics

**Relationship Based**
- family, friends, neighbors, co-workers, community members, church members

**Community-Based**
- school, businesses, church/faith based, public transportation, parks and recreation

**Eligibility-Specific**
- SHS services, Special Ed, Medicaid, section 8, Food Stamps, Vocational Rehab (VR)
The Arc StL
Problem Solving for Info and referral
Problem Solving:

Providing Support to Person with DD

- Personal Strengths & Assets
- Relationships
- Technology
- Community Based
- Eligibility Specific

Day to Day Support
Ben's Services and Supports

**PERSONAL STRENGTHS & ASSETS**
Able to stay home alone for up to an hour; has & can use i-pad;

**TECHNOLOGY:**
i-pad when home alone; digital watch

**RELATIONSHIPS:**
Mom, Dad, Matt, Zac, Ali, Chad, Ericka, Roy, Carol, Nick, Spohn,

**COMMUNITY BASED:**
Firemen at ESFD; coaches & staff at ES high school; Omni bus;

**ELIGIBILITY SPECIFIC**
DDD Self-Directed waiver PCA staff; Medicaid; Special Needs Trust

**Service and Support Needs**

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Template by Missouri Family to Family @ UMHC-VHD, UCODE December 2015
Eric’s Focus on Social and Spirituality

**PERSONAL STRENGTHS & ASSETS**
- Happy, Funny and loving
- Likes to help people
- Likes to try new things
- Police cars, tow trucks, fire engines and racecars
- Golf Cart

**COMMITTEE-BASED**
- Scouts
- Red Robin
- Race Tracks

**TECHNOLOGY-BASED**
- I-pad
- Smart Phone

**INTEGRATED SUPPORTS**

**RELATIONSHIP-BASED**
- See his girlfriend more
- Connect with his family
- Spend more time with friends

**ELIGIBILITY-BASED**
- Companion Supports
day-to-day
Project Outcome 2
Enhanced national and state policies, practices, and sustainable systems that result in improved supports to families.

Life Course Guiding Principles

- CATALYSTS
  - LISTENING TO SELF-ADVOCATE & FAMILY VOICE
  - VALUES
  - LEADERSHIP

- INFRASTRUCTURE
  - REFRAMING
    - SPACE FOR INNOVATION
    - POLICY & GOALS
    - FINANCING
    - TRAINING & TA
    - OUTCOME DATA

- INNOVATIONS
  - PRE-FRONT DOOR
  - SERVICE DELIVERY
  - MEDICAID WAIVERS
  - FAMILY NETWORK/PEER SUPPORT
  - WAITING LIST
  - PERSON/FAMILY-CENTERED PLANNING

- OUTCOME

*Adapted from SELN Systems Transformation Drivers and Framework

*Adapted from Hall et al, 2007
Mapping Supports

Discovery & Navigation (Info and Training)

Connecting & Networking (Talking to Someone that has been there)

Goods & Services (Day to Day, Medical, Financial Supports)
ALL: Public Health Framework

- Hand Washing
- Anti-Bacterial Soap
- Flu Shot
- Medical System
Constructing Universal Strategies for Supporting Individuals with Disabilities and Families Across the LifeCourse

- Family and Self-Advocacy Networks
- Aging and Disability Resource Centers
- No Wrong Door Initiatives
- Area Agencies on Aging
- Parent Training Info Centers for Education
- United Way 211

Accessed by all citizens:
- Faith based communities
- Parks and Recreation
- Businesses
- Emergency Personnel

Community Resources

Public-Private Partnerships

Government

Long Term Services and Supports
What is Our Vision for Supported Families?

Vision for Strong and Supported Families

Write down your responses on your worksheet & discuss with your table
What DON’T you want??

What happens when families aren’t supported?

Write down your responses on your worksheet & discuss with your table.
Innovations

- Front Door to Services
- Family Networks, Advisory Councils, & Peer Support
- Information Dissemination & Training
- Planning & Support Coordination
- Partnerships & Connecting Initiatives
- Policy (Medicaid, CMS)
Reframing for All Stakeholders: Developing Materials

Family to Family at Missouri UCEDD
Early Childhood, Part C
School Districts, Special Education
PNS Show Me Career Grant Pilot Sites
State Division of Developmental Disability
Special Health Care Needs
Dept. Health and Senior Services
Vocational Rehabilitation
Reframing for All Stakeholders: Focused Education and Training

- Self-Advocates and Families
- Partners in Policymaking Classes
- Person Centered Planners
- Teachers and School Professionals
- Employment Professionals
State Structures
Connecting Families to Support

State DD Agency
- Intake and Eligibility for State Division of DD and Medicaid Waiver services
- Person Centered Target Case Management and Support Coordination
- Provision and oversight of long term services and supports
- On-going quality enhancement and data collection of services and supports

Missouri F2F Resource Center
*Parent-to-parent peer support for families of CYSHCN:*
- Recruits and trains family mentors
- Maintains a pool of over 400 trained mentors
- Assists with creating timely and effective peer matches
- Provides follow-up support
- Evaluates outcomes
- Provides information on community resources
Eligibility
Services

DDS Services

Person Centered Planning

Community

Assistive Technology

Strengths & Assets Planning
Missouri Quality Outcome
Citizenship & Advocacy
People Have Opportunities to Advocate for Themselves, Others and Causes They Believe In, including Personal Goals and Dreams

State Structures
Person Centered Planning and HCBS Rules

Learning Opportunities Quality Works, Inc.
Initial and Annual Assessment

Consumer Name (first, middle initial, last name): ___
LOQW, Inc. Date of Birth: ___

Instructions for use: This assessment is used for initial or annual assessment. Meet with the individual and support members of their choice to ask each question in succession. Answers should be recorded in full written form so that when they are read to someone the answers are exact, without need to remember.

Initial Assessment Annual Assessment

Contributing staff or family: ___

Community Living
Living Arrangement:
Do you like where you live and who you live with? Are there any modifications in your home needed to (bath, stuff, suite, etc.)? Do you feel safe when you are at home?

Transportation and Community Access:
Are there easy places you like to go and how do you get there? What support do you need, if any, to access your community?

Is there anything you would like to learn how to do as a hobby or a special interest to you?

Social and Spirituality
Communication:
Who are your family and friends that are most important to you and what do you enjoy doing together?

How do you communicate with your family and friends (Verbal: Nonverbal, letters, phone, email, sign language, communication device) and in what way you could make more frequent contact?

*Icons: Each MOQO has a correlating “Charting the Life Course” icon to assist in using the guides together.

Daily Life
Community Living
Social Spirituality
Healthy Living
Safety & Security
Citizenship & Advocacy
Supports to Families

ABOUT THIS OUTCOME
This outcome emphasizes the importance of self-advocacy. Training and ongoing support are often time requirements to assist an individual in developing their self-advocacy skills.
Integrating Systems and Initiatives: Youth Transition and Employment

Supporting Families

Show-Me-Careers

Statewide Employment Leadership Network (SELN)

Employment First State Leadership Mentor Program

Office of Disability Employment Policy
Focus of CoP Supports to Families and DD System:

- Support Coordination
- Person Centered Thinking, Planning, and Facilitation
- Family Navigation and Family Networks
- LifeCourse Framework and Tools
- Responding to new CMS HCBS rule
- Focusing on Front Door of DD Services
State Structures

State Waitlists

Strategies:
1. Strengthen Information Access
2. Provide Resource Navigation and Improve Inter-Agency Service Coordination
3. Provide family-to-family support to individuals and families who are currently on the Waiting List or who apply for Waiver Services.
4. Assess needs of families currently on the Waiting List.
5. Build capacity of services and supports outside of those provided through DDS waivers.
State Structures
Medicaid State Plans and Waivers

Employment and Community First CHOICES Waiver for Tennesseans with I/DD (Amendment 2)

• Family Caregiver Education and Training
• Community Support Development, Organization and Navigation
• Peer–to-Peer Self-Direction, Employment and Community Support and Navigation
What does K Plan: Community First Choice change about our current system?

**Current:**

- **Entitlements (State Plan):**
  - Institutional
  - Home and Community-Based

- **Other Medicaid:**
  - Medicaid Personal Care:
    - Personal Care

- **Waivers:**
  - Personal Care
  - PERS
  - Equipment
  - Assistive Technology
  - Home Modifications
  - Respite
  - Therapies
  - Habilitation
  - Employment Support
  - Other

*Current: client is eligible for one or the other*

**Future:**

- **Entitlements (State Plan):**
  - Institutional
  - Home and Community-Based

- **Other Medicaid:**
  - Medicaid Personal Care:
    - Personal Care

- **New - Community First Choice:**
  - Required CFCO Services
  - Optional CFCO Services?
  - More Flexibility?
  - Improved outcomes

- **Waivers:**
  - Will look different in some cases
  - May become more of a wrap-around service to CFCO?

*New: A client is potentially eligible for both*
Type of 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
Transformational Change

Life Course Guiding Principles

CATALYSTS
- Listening to self-advocate & family voice
- Values
- Leadership

INFRASTRUCTURE
- Reframing
  - Space for innovation
  - Policy & goals
  - Financing
  - Training & TA
  - Outcome data

INNOVATIONS
- Pre-front door
- Service delivery
- Medicaid waivers
- Family network/peer support
- Waiting list
- Person/family-centered planning

OUTCOME

Adapted from Hall et al., 2007

*Adapted from SELN Systems Transformation Drivers and Framework
Transitional Change: Innovations

Life Course Guiding Principles

CATALYSTS

Values

Leadership

LISTENING TO SELF-ADVOCATE & FAMILY/SERVICE

INFRASTRUCTURE

REFRAMING SPACE FOR INNOVATION
POLICY & GOALS
FINANCING
TRAINING & TA
OUTCOME DATA

INNOVATIONS

PRE-FRONT DOOR SERVICE DELIVERY
MEDICAID WAYSERS
FAMILY NETWORK/PEER SUPPORT
WAITING LIST
PERSON/FAMILY-CENTERED PLANNING

OUTCOME

PARTNERSHIPS

Michelle “Shell” Reynolds, PhD. UMKC Institute for Human Development, UCEDD. Revised June 2014. Adapted from Hall et al, 2007
www.siblingleadership.org

**Mission:** To 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.
Background

• Founded in 2007, the SLN is a national nonprofit with state chapters

• Supporting sibling across the lifespan

• Welcome to sibs of all types of disabilities—tend to draw sibs of people with I/DD

• Developed a policy white paper with recommendations on policy and advocacy, research, and services and supports
State Chapters

• Alabama  • Maryland  • Ohio
• California  • Massachusetts  • Pennsylvania
• Colorado  • Michigan  • South Dakota
• DC  • Minnesota  • Tennessee
• Georgia  • New Hampshire  • Utah
• Illinois  • New Jersey  • Virginia
• Kentucky  • New York  • Wisconsin

To develop a chapter, contact the SLN Chair of Network Development, Erin Hutzelman, at chapterinquiries@siblingleadership.org
State Chapters

Sibling Leadership Network State Chapters

Join the SLN

- Visit www.siblingleadership.org
- Find us on Facebook at
  - http://www.facebook.com/siblingleadership
- Email info@siblingleadership.org
Join a Committee

- Research
  Email: research.inquiries@siblingleadership.org

- Support and Information
  Email: support.inquiries@siblingleadership.org

- Policy and Advocacy
  Email: policy.inquiries@siblingleadership.org

- Communications
  Email: communications.inquiries@siblingleadership.org

- Chapter Development
  Email: chapter.inquiries@siblingleadership.org
Save the Date!

SIBLING LEADERSHIP NETWORK

2017 National Conference

June 24 & 25
Hartford, Connecticut
Year 4&5:
Supporting Families
Focus Areas

Providers Partnering with Families
Self-Directed Supports and Families
Goods and Services Specific to Family or Caregiver
Building Capacity of Community to Support Families
Project Outcome 3
Enhanced capacity of states to replicate and sustain exemplary practices to support families and systems.

Phase II: Community of Practice Starting in 2016
Contact Information

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reynoldsmc@umkc.edu