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

OVERVIEW OF THE LIFECOURSE FRAMEWORK

JANUARY 22, 2015
About Us....

Mary Lee Fay
Formerly Director of State Developmental Disability Services in Oregon
NASDDDS, Co-Principal Investigator CoP and National Core Indicators

Sheli Reynolds
Sibling of brother with developmental disability
IHD, Mo UCEDD, Director of Individual Advocacy and Family Supports
Co-Principal Investigator 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 than include a member with I/DD across the lifespan.

Project Outcome
• 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.
Funded by

National Partners

NASDDDS

UMKC

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

HSRI

SELF ADVOCATES BECOMING EMPOWERED

AUCD

ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
RESEARCH, EDUCATION, SERVICE

NACDD
SUPPORTING FAMILIES
of individuals with intellectual & developmental disabilities
THE NATIONAL COMMUNITY OF PRACTICE • FUNDED BY THE ADMINISTRATION ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES

CT  DC  MO

OK  TN  WA
National CoP Structure

Y1-2: Technical Assistance from National Staff

- Monthly Calls with All States
- One on One TA calls with Teams or Facilitator
- Yearly Face to Face Meeting
- Annual TA visit in states
- Topical Specific Webinars (Family Networks, Framing)

Y3-5: TA and Knowledge Translation

- National Webinars on Learning
- Issues Briefs
- E-newsletter
- Increased Social Media Presence
**Defining Supports to Families**

**GOAL**

**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 the individual to achieve their goal.

Recognizing that individuals exist within a family system.

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**DISCOVERY & NAVIGATION**
Knowledge & Skills

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

**GOODS & SERVICES**
Day-to-Day & Caregiving/Supports
Integration of All Movements

1950s Parent----Family-----Siblings

1960s State Service Systems
1970s Education for Children with Disabilities
1980s Medicaid Waiver

1970s Self-Advocacy-----Youth

2010s Community

LifeCourse Framework
Guiding Principles & LifeCourse Framework

Reframing the Conversation at All Levels
People with disabilities and their families have the right to live, love, work, play and pursue their life aspirations just as others do in their community.
Focus on “ALL”

ALL individuals with disabilities and families are considered in our values and vision.

(Family is defined by Individual)
Focusing on ALL

All 4.9 Million people with developmental disabilities

75%

25%

National % Receiving State DD Services

Based on national definition of developmental disability with a prevalence rate of 1.49%
Missourians with I/DD

95,498 estimated Missourians with Developmental Disabilities

65% (62,498)

19%

13%

3%

ICF/DD

Enrolled HCBS

DD Services

State DD Services

Targeted Case Management

Based on 1.58% prevalence of 3.815 million citizens, US Census
Oklahomans with I/DD

60,277 estimated Oklahomans with Developmental Disabilities

73% (44,002) 12% 15%

Enrolled State DD Services
Waiting for State DD Services

Based on 1.58% prevalence of 3.815 million citizens, US Census
All individuals live within the context of a family

*Individual members and their family, as a whole, may need supports that address different facets of life and that adjust as roles and needs of all family members change as they age through both the life cycle and the family cycle.*

*(Regardless of where a person lives)*
Importance of Family within the Context of Disability Services: Our History
Importance of Family within the Context of Disability Services: Current Supports

89% of People I/DD receiving services are Supported by Family

4.7 Million people with I/DD

- Receiving Services Out of Home 13%
- Receiving Services Living at Home 12%
- Not Receiving Services - Living at Home 75%

Recognition of Individual and Family Cycles

**Individual Life Cycle**
- Birth
- Early child
- School
- Transition
- Adulthood
- Aging

**Family Life Cycle**
- Single Adult
- New Couple
- Couple with Children
- Launching Children
- Family Later in Life
### Reciprocal Roles of ALL Family Members

<table>
<thead>
<tr>
<th>Caring About</th>
<th>Caring For</th>
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</thead>
<tbody>
<tr>
<td>Affection &amp; Self-Esteem</td>
<td>Provider of day-to-day care</td>
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<td>Repository of knowledge</td>
<td>Material/Financial</td>
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<tr>
<td>Lifetime commitment</td>
<td>Facilitator of inclusion and membership</td>
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<td>Advocate for support</td>
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</table>

# Life Stages: Think Across Generations

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<tr>
<th>Age</th>
<th>0-5</th>
<th>6-18</th>
<th>19-64</th>
<th>65</th>
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<tbody>
<tr>
<td>Total TN Population</td>
<td>406,659 (6.3%)</td>
<td>1,084,425 (16.8%)</td>
<td>4,047,231 (62.7%)</td>
<td>916,597 (14.2%)</td>
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<tr>
<td>Approx. DD (1.59%)</td>
<td>6,465</td>
<td>17,242</td>
<td>64,350</td>
<td>14,573</td>
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</table>
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
Focusing on Life Experiences

“Anticipatory Guidance for Life Experiences”
# Thinking Across All Life Domains

<table>
<thead>
<tr>
<th>Daily Life &amp; Employment</th>
<th>What a person does as part of everyday life – school, employment, volunteering, routines, life skills</th>
<th>Healthy Living</th>
<th>Managing and accessing health care &amp; staying well – medical, mental health, behavioral health, developmental, wellness &amp; nutrition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Living</td>
<td>Where and how someone lives – housing and living options, community access, transportation, home adaptations &amp; modifications</td>
<td>Safety &amp; Security</td>
<td>Staying safe and secure – emergencies, well-being, guardianship options and alternatives, legal rights and issues</td>
</tr>
<tr>
<td>Social &amp; Spirituality</td>
<td>Building friendships and relationships, leisure activities, personal networks, faith community</td>
<td>Citizenship &amp; Advocacy</td>
<td>Building valued roles, making choices, setting goals, assuming responsibility and driving how one’s own life is lived</td>
</tr>
</tbody>
</table>
Three Types of Supports

- Discovery & Navigation
- Connecting & Networking
- Goods & Services
Identifying Integrated Strategies for Delivery Supports

Not only DD Services
Self-Advocates and Families Must Engage, Lead, and Drive Policy and Systems Change
Applying the Framework to Transformational Change

“Creating Space for Innovation”
ALL: Public Health Framework

Hand Washing
Anti-Bacterial Soap

Flu Shot

Medical System
Developing Innovative Strategies for Transformation within and outside DD

Eligibility Based Supports

- Family and Self-Advocacy Networks
- ADRC No Wrong Door Initiatives
- Inclusive education with supports
- Adaptive equipment
- Problem Solving and Life Navigation

Universally designed and affordable homes
Grocery carts for older kids
EMT and Police knowledgeable and supportive
Strong families and friends to share lives with
Inclusive and accepting spiritual and recreational opportunities
Building Family & Self-Advocacy Networks

**Missouri:**
- Statewide Family to Family Network consisting of 150 affiliates and over 900 self-advocate and family leaders
- State agency contracted with Family to Family Health Information Center for seamless front door

**District of Columbia:**
- State is partnering with other state agencies and has contracted with P2P USA to start DC chapter
- Training Family Facilitators on One Page Profiles
Applying Life Trajectory: Systems

Life Trajectory Worksheet: Individual

Everyone wants a good life. The bubbles on the right will help you think about what a good life means for you or your family member and identifying what you know you don’t want. You can use the space around the arrows to think about current or needed life experiences that help point you in the direction of your good life.

Vision for a Good Life

- Education
- Career
- Job of Choice
- Economic Sufficiency
- $ for Home & Fun

What I DON’T Want

- Poverty
- No opportunities
- Sheltered Employment
- Dependence on Govt

Missouri Family to Family | UMKC-IND, UCDDD

May 2014
Applying Life Trajectory: Practice

CHARTING the life course

TRAJECTORY WORKSHEET

Daily Life & Employment

0-5 years
- Multiple Environments (family, daycare, church)
- Socialization
- Learning
- Early intervention
- Access to health care

6-12 years
- What do you want to do/be?
- Manners
- Social skills
- Electronics
- Learning
- Responsibility
- Learning
- Independence
- Exposed to world
- Expectations
- Communication

13-18 years
- Problem solving
- Mistakes/risk
- Consequences
- Value of choices
- Value of money
- Recognize Strengths/Weaknesses
- Aware of others
- Self-awareness
- Learning to fill out applications
- Setting goals
- Having experiences
- Accepting limits

Facilitator: Mary Katherine Long
Monitor: Carla McCarrell-Williams

VISION for the Life I WANT

- Love and happiness
- Friends
- Having a purpose/feeling valued
- Involvement in the community
- Healthy-good health
- Family
- Success-successful relationships
- Jobs
- Hobbies
- Stability
- Safety (relationships)
- To feel safe: safe environment, with people
- Choice
- Independence
- Feeling valued
- Financial security
- Home
- Access to needs
- Transportation-for all

What I DON'T Want

- Only one option
- Boredom
- Poor health
- No control
- Poverty
- Loneliness
- Crisis
- Hopelessness
- Abuse
- Sadness
- Lack of acceptance
- Isolation

MISSOURI FAMILY TO FAMILY | UMKC-IHD, UCEDD
Applying Life Trajectory: John

Vision for a Good Life
* Visit Mom/spend time as she gets older
* Making good $, job I love
* Moving forward ➔ Home, Internet
  Being my own guardian—don’t want to rush, being in control of $, not having limits
* Living alone—no roommate, growing staff
  Transportation & checks
* Doing more lawn/snow blowing business
* Not getting bailed out!
  Getting support on my own terms

What I DON’T Want
- Lose job
- Not having reliable transportation
  Not feeling trapped, restricted, stuck
- Not being in placement rest of your life
- Others making the rules/decisions
Application of the Integrated Supports Star
System Level: Connecticut
Organizational Level: Connecticut

- Eligibility Services
- Community
- DDS Services
- Assistive Technology
- Strengths & Assets Planning

Person Centered Planning
Individual Level: Ben
The GOOD LIFE is getting tatted up!
BEN’S INTEGRATED SUPPORTS

TECHNOLOGY BASED
- I-pad, “apps”, Facebook, Facetime, Digital watch, Vibrating toothbrush, Glasses

PERSONAL STRENGTHS & ASSETS
- Outgoing, friendly, Eagle Scout, ability to ride city bus, Dad’s fire & police connections

RELATIONSHIP BASED
- Dad, Mom, Matt, Zac, Ali, Chad, Ericka, Sheli, Firemen friends, Ange, Pam, Wally, Josh B., Matt S., Mike, Nick, Scouting friends

COMMUNITY-BASED
- Omni bus, Walmart, 24 Hour Fitness, Library, Price Chopper, Scout Troop, Dr. T., St. Ann’s church, ES Fire Department, joint bank account, direct deposit

ELIGIBILITY-SPECIFIC
- PCA – DDD, Self-directed supports, Social Security, Medicaid, Special Needs Trust
Integrating Supports into Real Life

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**Long Term Service and Support Needs**

Parents get Ben out of bed, assist with breakfast, shower, getting dressed and ready for his day. Parents support Ben. Waiver Self-Directed PCA.

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**Long Term Service and Support Needs**


**Mom and Dad provide all support, including meals, transportation and support for activities, etc.**

Mom and Dad are overnight staff.

**Mom and Dad prepare meal as needed.**

Mom and Dad are overnight staff.
Building Teams: Life Stages and Life Domains

- Pediatrician, Families and Friends, Faithbased
- 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
CoP Teams: Connecting Initiatives

- Employment First
- Alternatives to Guardianship/Supported Decision Making
- No Wrong Door Initiatives
- Aging and Disability Resource Center
- CMS Balanced Incentive Program
- CMS Community Settings and Person Centered Rule
- Family Information Systems Project
- NIDRR newly funded RRTC on Family support
- IDEA Performance Outcomes
- HRSA Home Visiting
Applying to Wait List Discussions

60,837 estimated Oklahomans with Developmental Disabilities

73% (49,319) Names on Waiting List for Waiver Services

11.5% Receiving Waiver DD Services

7.5% Not Named on Waiting List

Information about Oklahomans with DD on Waiting List

<table>
<thead>
<tr>
<th>0-5</th>
<th>6-18</th>
<th>19-64</th>
<th>65+</th>
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<tr>
<td>624</td>
<td>2579</td>
<td>3714</td>
<td>59</td>
<td>6,976</td>
<td>Names on Waiting List</td>
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<tr>
<td>114</td>
<td>620</td>
<td>850</td>
<td>11</td>
<td>1,695</td>
<td>On list, No known public benefits</td>
</tr>
<tr>
<td>510</td>
<td>1959</td>
<td>2864</td>
<td>48</td>
<td>5281</td>
<td>On list, Getting Some Public benefits</td>
</tr>
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</table>
Putting Framework Into Action

Partnering to Disseminate a Consistent Message

- Early Childhood and Part C
- School Districts, Special Education
- PNS Show Me Career Employment Grant State
- Division of Developmental Disability
- Special Health Care Needs
Overall Themes: What are we learning?

• Balancing Focus on Person with Disability as we try to increase supports to families
• Concept of “all” has made a major impact
• Family support vs. supporting families
• Aging families or “traditional mindset” families comfortable with the current system
Overall Themes: What are we learning?

• Thinking about integrated supports
  • Technology is really exciting
  • Increased focused on what are “natural or informal supports”

• People are “ready” and excited for the message and concrete, practical tools

• The skill of “partnering” with other entities and with self-advocates and families is hard
Learning: System Level

• Initial focus within State Developmental Disability system policies and practices
• Partnering and integrating framework within other systems (VR, Education, Aging)
• Integrating Person Centered Thinking and Planning with LifeCourse Framework
Learning: Practice Level

- Development and piloting of LifeCourse training materials and tools for different target audiences (Self-Advocates/Family, Case managers, Options Counselors, Teachers, Family Navigators)

- Initial phase of developing an implementation structure of facilitators and trainers to ensure competency and fidelity of practices
Questions, Reflections and Discussion
Innovations Webinar Series

Next Webinar:
Focusing on the Front Door of Supports

Future topics:

- Emotional/Navigational Peer Support
- National & State Data Projects
- Person-Centered & LifeCourse Planning
- Medicaid Waivers and Other Funding Sources
- Waitlist for Services
Contact Information
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