Our Learning from Six States in the Community of Practice

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HCBS Conference
Outcomes for Today

• Overview of the National Community of Practice on Supporting Families
• Introduce the framework for “reframing the conversation and solution finding” at all levels
• Share key areas of learning in States
• Discuss next steps and ways for others to get involved
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

[Logos of various organizations]
Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities

CT  DC  MO
OK  TN  WA
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*
Long Term Goal
“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 the individual to achieve their goal.
REFRAMING OUR THINKING

What have we learned? Reframing the Conversation at All Levels
Systems Change Framework

*Adapted from SELN Framework*
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%
The FAMILY is a SYSTEM!!

There are FAMILY CYCLES!!
INDIVIDUALS live within the context of THEIR FAMILY
## Reciprocal Roles of Family Members

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

Both in practice with individuals and in policy changes for systems
Thinking About All Life Stages

Both in practice with individuals and in policy changes for systems
Bigger than Family Support: Requires Organizing Culture, Policies and Practices

Birth-----Early Child----School----Transition---Adulthood-----Aging
REFRAMING OUR PRACTICES AND POLICIES
Supports should Enhance Real Lives

PERSON

FAMILY

COMMUNITY
Current Support System

- Community
- Family
- Services
- Person
Real People, Real Lives with Integrated Supports
### 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 healthcare &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>
Support Physical, Emotional, Intellectual and Financial Well-being

<table>
<thead>
<tr>
<th>Discovery &amp; Navigation: Knowledge &amp; Skills</th>
<th>Connecting &amp; Networking Mental Health &amp; Self-efficacy</th>
<th>Day-to-Day Services Instrumental Supports</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Information on disability</td>
<td>• Parent-to-Parent Support</td>
<td>• Self/Family-Directed services</td>
</tr>
<tr>
<td>• Knowledge about best practices and values</td>
<td>• Self-Advocacy Organizations</td>
<td>• Transportation</td>
</tr>
<tr>
<td>• Skills to navigate and access services</td>
<td>• Family Organizations</td>
<td>• Respite/Childcare</td>
</tr>
<tr>
<td>• Ability to advocate for services and policy change</td>
<td>• Sib-shops</td>
<td>• Adaptive equipment</td>
</tr>
<tr>
<td></td>
<td>• Support Groups</td>
<td>• Home modifications</td>
</tr>
<tr>
<td></td>
<td>• Professional Counseling</td>
<td>• Financial assistance</td>
</tr>
<tr>
<td></td>
<td>• Non-disability community support</td>
<td>• Cash Subsidies</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Short/Long term planning</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Caregiver supports &amp; training</td>
</tr>
</tbody>
</table>
Identifying Integrated Strategies for Delivery Supports: *Not only DD Services*

- **Relationship based supports**
  - Family, friends, neighbors, co-workers, community church members

- **Community based supports**
  - School, public transport, businesses, church, parks and recreation

- **Technology based supports**
  - iPad/smart phone “apps”, remote monitoring, cognitive accessibility, adaptive equipment

- **Eligibility specific supports**
  - Mental disability services, special education, Medicaid, food stamps, section 8, vocational rehabilitation
Inter-Agency Collaboration and Partnerships

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
Developing Innovative Strategies for Transformation within and outside DD

- Eligibility Based Supports
  - Family and Self-Advocacy Networks
  - 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
What is happening in the CoP States?

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

- Two full time people in Central office to focus on systems change to support families
- Cross department life span team
- Creating Consistent Message
- Focusing on “community teams” with new partners
- Enhancing eligibility process to be more family friendly
- Supporting the development of Sibling Network
Connecticut

• Community Teams
  – Information Dissemination
  – Family Mentoring and Leadership
  – Training and Education
  – Self-Directed Services and In-Home Supports
  – Social Supports and Respite
  – Positive Behavior Supports
  – Person Centered Housing
  – Employment
  – Healthy Living
  – Technology
Connecticut

Person Centered Planning

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

COMMUNITY OF PRACTICE FOR SUPPORTING FAMILIES

MISSION
To discover, design and deliver effective supports for families who have a family member with a disability.

FOUR YEAR VISION OF SUCCESS
360 degrees of support. Families feel surrounded by support. This cannot be done by just shifting the buckets of money. It must be done by engaging with communities.

FAMILIES FEEL BETTER ABOUT THEIR LIVES BECAUSE THEY HAVE ACCESS TO:
• MENTORING to increase their Personal Power. Each individual in the family feels greater confidence in their individual role (parent, sibling, grandparent, self-advocate, etc.).
• FAMILY GROUPS to increase their Family's Power. Families feel more powerful because they are able to support one another through groups and community connections.
• COMMUNITY COLLABORATION to increase their Civic Power. Most family issues (health, safety, social, home, school, employment, etc.) are addressed in common ways in their communities just like any other citizen—unique needs are met as needed for only as long as needed.

VALUES
• COMMUNITY: Our job is to help people with disabilities be part of the larger world, not just the disability world. Community needs to be a central feature of all that we do.
• LIFESPAN: All of our work needs to be built upon a lifespan approach. We cannot do our work in isolated stages. Each lifespan stage is built upon what has occurred in a previous stage. We need to work together across all ages.
• STRENGTHS AND COMMONALITIES: A focus on scarcity of resources or on fears produces short term solutions to the challenges we face. The discovery and building upon commonalities, strengths and “what works” will lead us to better, more sustainable solutions for the long term.
• INNOVATION: Innovation is good. Sustainable innovation is better. Scalable innovation is best. We need to make sure proposed innovations will work for many, not just a targeted few.
• TEAMS: It takes a team to create solutions to the barriers we face in designing more effective supports for families. We need architects to help use and design creative support models. We need contractors who can help us transform the design models into everyday practices. We need workers who can make sure the contractors ideas are implemented properly so that the design is a well-made structure. Families and individuals also need to modify and adapt what we do in ways that meet their individual needs. We need you.

A COLLABORATION BETWEEN

CT Council on Developmental Disabilities
council.ct.gov

CONNECTICUT

STRATEGIES TO SUPPORT REAL LIVES
RESOURCES & SERVICES ALONG THE LIFESPAN

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LEARN ABOUT THE NATIONAL CoP
VISIT
supportoffamilies.org
District of Columbia

• Legacy system
  – Adults with Intellectual Disabilities only
  – Commitment to community based supports
  – Stalled at reforming the law

• System Reform Initiatives
  • Employment First
  • Person Centered Thinking
  • Supporting Families CoP
District of Columbia

Examples of Levels of Change

• DDA
  – Stipends
  – Policy Review Committee
  – Regulatory change and waiver amendments
  – Plans for Parent to Parent Support

• DDC
  – Partners in Policy Making

• UCEDD
  – Web-based resource for families

• Quality Trust
  – Training and capacity building for families
• Build on longstanding family involvement activities:
  – Strong involvement of Family Voices and UCEDD Family Leadership Advisory Council
  – Trained Family Advisory members on LifeCourse framework
  – Focused Annual Joining Forces Conference on LifeCourse and Supports to Families
  – Resulted in Rural Family Institutes using LifeCourse Framework for training workshops
• State DD System focusing on role of case managers working with families
• Blue Ribbon Task Force using LifeCourse framework to guide conversations and plan development
Oklahoma

• State DD System
  – Existing initiatives focused on person centered planning
  – Enhance role of case managers and intake workers support to families

• Governors Blue Ribbon Task Force using LifeCourse framework to guide conversations and plan development
Washington

Infused the lifecourse framework into existing “Informing Families, Building Trust” messaging efforts
Washington

• Strong leadership and partnership of state DD Council with State DD system
• Recommendations made to integrating “supporting families” framework and specific services into the new states K Plan
• Exploring “a family component” into already strong use of NCI data to drive systems change
Hosting focus groups based on a newly recognized need to “ask questions differently” and to target specific groups to guide ongoing systems activities:

- Families on the “no paid services”
- Aging Caregivers
- Transition Age Families
- Parents with Disabilities
- Siblings
Tennessee

Three major focus areas:

• Tools for Re-Framing: Communication strategies, Information Dissemination
• Focus on the ‘Front Door’ to Services
• Target Activities for Those Waiting for services (7,000+ in TN)
Tennessee

Communication Tools for Reframing
(e-newsletter, magazine, folder, website, social media)
Leveraging Current Opportunities

- Previous experience with Person-Centered Practices Community of Practice
- On way to being 1st state DD system to achieve Council on Quality Leadership accreditation
- 3 major employment grants (Labor, DIDD, & Vanderbilt / UCEDD)
  - “TennesseeWorks”: UCEDD grant, but also operates as an overarching stakeholder group
  - Gov.’s “Employment First Exec. Order”, Employment First Task Force to plan strategies for increasing employment for Tennesseans w/ I/DD
  - Many CoP state team members are on leadership teams for employment grants
  - TennesseeWorks: family survey, community conversations, family coalitions
Tennessee

Building new opportunities

• Governor’s Children’s Cabinet
• University of TN Strengthening Families initiative – *policy seminar focused on educating policymakers about needs of all families*
• State Interagency Coordinating Council (for Early Intervention Services)
• New Parent-to-Parent Mentoring program through Dept. of Mental Health grant
DMH DDD contracted with UMKC-UCEDD and its Family to Family Resource Network on “supporting families” activities, such as:

- Process consulting to key leadership on applying lifecourse framework to policy and practices
- Training and technical assistance to Family Support Coordinators and other Statewide Leads
- Establishment of new state DD intake procedures and capacity to seamlessly refer families to F2F for Information and Peer Support
Missouri

• DD Council and LifeCourse Framework
  – Long term partnership with UMKC and Family to Family Resource Network
  – Used LifeCourse Strategic Planning Tools to:
    • Organize Council Retreat
    • Map and Align projects, staff and efforts
  – Integrated LifeCourse and Supporting Families into Partners in Policymaking curriculum and alumnae weekend
Missouri

Development and Integration of LifeCourse Tools
Identifying Key Drivers and Indicators for Systems Transformation and Implementation

*Adapted from SELN Framework
Capturing Our Learning

Stages of Development

Potential
- People face similar situations without the benefit of a shared practice
- Finding each other, discovering commonalities

Coalescing
- Members come together and recognize their potential
- Exploring connectedness, defining joint enterprise, negotiating community

Active
- Members engage in developing a practice
- Engaging in joint activities, creating artifacts, adapting to changing circumstances, renewing interest, commitment, and relationships

Dispersed
- Members no longer engage very intensely, but the community is still alive as a force and a center of knowledge
- Staying in touch, communicating, holding reunions, calling for advice

Memorable
- The community is no longer central, but people still remember it as a significant part of their identities
- Telling stories, preserving artifacts, collecting memorabilia

Typical Activities

time
Capturing Our Learning
supportstofamilies.org
Questions, Reflections and Discussion
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