National Community of Practice on Supports to Families and the Lifespan Respite TA Center

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Setting the Stage?

How is the work of supporting families with members with I/DD connected to Lifespan Respite?
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.
Focus on “ALL”

ALL individuals and their families are considered in our values and vision.
1 in 5 Americans with Disability

9.4 million individuals have difficulties with activities of daily living (eating, bathing, dressing)

  5 million required assistance

15.5 million individuals have difficulties with instrumental activities of daily living (housework, phone, meal preparation)

  12 million required assistance

(Americans with Disabilities 2010, U.S. Census Bureau)
People with I/DD

All 4.9 Million people with developmental disabilities

- 75% Unaware of disability specific services
- 25% Do not want disability specific services
- Have a diagnosis but don’t meet “eligibility criteria” in that state system

National % Receiving State DD Services
Where Adults with I/DD Live

89% of People I/DD are Supported Outside of Formal Residential Supports

- 3,500,000 (75%) Living at Home
- 528,000 (13%) Receiving Services Out of Home
- 672,000 (12%) Not Receiving Services - Living at Home

4.7 Million people with I/DD

National, State and Local Transformation

Policy, practice and community change across all populations across the lifespan
Every System has the Same Current Realities!

- Expectations, Values, Culture
- Policies and Budget
- Evidence Based Practices
- Demand for Services
- Language and Words
- Social and Medical Services
- Person with Disability
- Family
- Community
All Social Services and Supports are Evolving
Our Transformation Strategy: Public Health Analogy

Medical System

Flu Shot

Hand Washing

Anti-Bacterial Soap

Medical System
Constructing Universal Strategies for Supporting Individuals with Disabilities and Families Across the LifeCourse

Community Resources
- Faith based Organizations
- Community Centers
- Neighbors, family

Public-Private Partnerships
- Family and Self-Advocacy Networks
- Lifespan Respite Organizations
- Local Respite Organizations
- Aging and Disability Resource Centers
- No Wrong Door Initiatives
- Area Agencies on Aging
- Parent Training Info Centers for Education

LTSS
- Long Term Services and Supports Systems
Services and Systems that Focus on the Person Within the Context of Their Family

(Regardless of where a person lives)
“A Good Life for All”
Supporting Families LifeCourse Framework
All people have the right to live, love, work, play and pursue their dreams 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.
Defining FAMILY

Family are those people who…
Consider themselves a family (whether or not they are related by blood or marriage) and support and care for each other on a regular basis
This is not dependent on where they live.

(Turnbull and Turnbull, KU Beach Center)
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

family

individual
<table>
<thead>
<tr>
<th>Caring About</th>
<th>Caring For</th>
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<tbody>
<tr>
<td>Affection &amp; Self-Esteem</td>
<td>Provider of day-to-day care</td>
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<tr>
<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>
</tr>
<tr>
<td></td>
<td>Advocate for support</td>
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The future is not something we enter. The future is something that we create. And creating that future requires us to make choices and decisions that begin with a dream.

-Vision for a Good Life

-Leonard L. Sweet
Three Types of Supports

- **Discovery & Navigation (Info and Training)**
- **Connecting & Networking (Talking to Someone that has been there)**
- **Goods & Services (Day to Day, Medical, Financial Supports)**
Focusing on Life Experiences

“Anticipatory Guidance for Life Experiences”
Think Across Life Stages and Generations

<table>
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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><strong>MD Total Population</strong></td>
<td></td>
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<td>368,201</td>
<td>1,348,093</td>
<td>3,426,651</td>
<td>795,790</td>
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<td>(6.2%)</td>
<td>(22.7%)</td>
<td>(57.7%)</td>
<td>(13.4%)</td>
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<td><strong>DD MD (1.58%)</strong></td>
<td>5,817</td>
<td>21,299</td>
<td>54,141</td>
<td>12,573</td>
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<td><strong>Known or Active in MD DDA</strong></td>
<td>314</td>
<td>4911</td>
<td>21,897</td>
<td>1,438</td>
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</table>

Based on 1.58% prevalence
5,938,737 citizens, US Census 2013
Based on May 2015 Data from MD DDA
Thinking Across all Life Domains

Daily Life and Employment (education/employment, life skills)

Community Living (housing, transportation, community access)

Social and Spirituality (friends, relationships and leisure activities)

Healthy Living (medical, behavioral and mental health, wellness, nutrition)

Safety and Security (emergencies, legal, well-being, guardianship and alternatives)

Citizenship and Advocacy (leadership, peer support, making choices, setting goals)
Developing and Integrating Supports and Services

**PERSONAL STRENGTHS & ASSETS**
- Person or family resources, abilities, strengths, characteristics

**COMMUNITY-BASED**
- School, businesses, Church/faith based, public transportation, Parks and recreation

**TECHNOLOGY-BASED**
- i-pad/smart phone apps, remote monitoring, cognitive accessibility, adaptive equipment

**RELATIONSHIP-BASED**
- Family, friends, neighbors, co-workers, community members, church members

**ELIGIBILITY-BASED**
- Disability Services, Special Education, Medicaid, Housing, Food Stamps, Vocational rehab (VR)
Partnering with Person with Disability and their Families so they can Engage, Lead, and Drive Their Own Lives and Policy, Systems and Community Change
Specific Partnering Activities
National CoP Focus on Respite

Discovery & Navigation
(Info, Training, Navigation, Planning)

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

Goods & Services
(Day to Day, Medical, Financial Supports)

Identify Respite options for families
Connecting with other Caregivers
Respite as a form of caregiver support
Year 1: Grant TA Activities

Phase I: Development of LifeCourse Tools for Assessing Respite Natural Supports

A. Form ARCH and National CoP Workgroup for 4 virtual meetings (2 hours each) for guidance on:
   1. LC Respite materials and training
   2. Strategies to Pilot LC Respite materials and training with interested Respite states
   3. Identification of “scaling up” pathways for capacity building and implementation use of LC Respite materials
Year 2: Grant TA Activities

Phase II: Training for State Lifespan Respite Grantees and Partners

A. Host 2 hour educational and training webinar on LC Respite materials

B. Facilitate 2 technical assistance follow-up calls with state grantees

C. Host webinars and materials on national and state websites
Example of Educational Tool using Integrated Star

**Technology**
- Smart Phone
- Telephone
- Computer

**Decision Making**
- Ability to communicate wants, needs, and wishes (traditional, sign, gesture, communication device)

**Money Management**
- Understands concept of money

**Personal Safety**
- Knows address, phone, other contacts
- Carries ID
- Disaster or Emergency Plan
- Ready bag for emergencies

**Safety & Security: Options & Alternatives to Guardianship**

**Decision Making Supports**
- Personal Contract or Agency Agreement
- Power of Attorney – General
- Power of Attorney for Health Care
- Supported (Shared) Decision Making

**Money Management**
- Joint Bank Account

**Personal Safety**
- Close Family & Friends

**Relationship Based**

**Decision Making**
- Medical Advisors (Doctor, Nurse)
- Clergy or Life Coach
- Financial Advisors
- Educational Advisors (Teacher, Counselor)

**Money Management**
- Limited Bank Account
- Direct Deposit
- Automatic Bill Pay

**Personal Safety**
- Neighbors
- Police
- Fire
- Emergency Medical Responders

**Community Based**

**Example of Educational Tool using Integrated Start**
Examples of LifeCourse Exploration Toolkit

LifeCourse Tools for Identifying and Exploring Respite Options for Caregivers and Families
Supporting Good Lives!
Life isn’t about how to survive the storm, but how to dance in the rain.

-unknown
Questions, Reflections and Discussion
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