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2011 Building a National Agenda for Supporting Families With a Member with Intellectual and Developmental Disabilities (Wingspread Report)

- Develop and fund a National Supporting the Family Initiative (not the same as family support services)
Project Goal:
To build capacity through a community of practice across and within the States to create policies, practices and systems to better assist and support families that 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
Supporting Families: A National Project

- 5 year grant from Administration on Intellectual and Developmental Disabilities
- Awarded to 6 states – in each state, grant is co-facilitated by the state’s DD service system agency and the DD Council
- Our state:
  - TN Dept. of Intellectual and Developmental Disabilities (DIDD); and
  - TN Council on Developmental Disabilities
Supporting Families: A National Project

- Six states selected to participate in this ‘community of practice’
  - Connecticut
  - District of Columbia
  - Oklahoma
  - Tennessee
  - Washington state
  - Missouri – mentor state

- “Community of Practice” = group doing an intensive exploration of policies, practices, trends, barriers
Supporting Families: A National Project

- Supporting families is defined as a set of strategies targeting the family unit but that ultimately benefit the person with I/DD.

- Recognizing that people exist within a family system.
  - **The person** – self determination, independence, productivity, integration and inclusion.
  - **The family** – supported to maximize capacity, strengths, unique abilities to nurture, love and support the person to
Why focus on families?

- 100% 4.9 million citizens with developmental disabilities
- 75% national percentage receiving state DD services
- 25%

(Based on 1.49% prevalence, US Census 2013) (Braddock et al, State of the State 2013)

Families are connected biologically.
Families are connected socially.
Families are connected environmentally.
Families are connected at all policy levels.
Why is this important? Why now?

- Families are providing care to the vast majority of people with disabilities in TN
- State/federal funding diminishing
- Waiting list for services increasing
- Impact of baby boom generation
  - Aging caregivers no longer able to support adult children with disabilities
  - Caregivers may need their own long term services and supports
Life Course Guiding Principles

Life is a journey – Our lives are not static, they change every day.

It’s all about vision – Anything is possible, with the right vision.

Everything is connected – What you do today affects your life in the future.

Our overall compass for people and their families “quality of life.”
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

Sheli Reynolds, PhD. UMKC Institute for Human Development, UCEDD. Revised June 2014. Adapted from Hall et all, 2007
Life Course Guiding Principles
Family, friends, neighbors, co-workers, community members, church members

School, public transportation, businesses, church, parks and recreation

iPad/smart phone “apps”, remote monitoring, cognitive accessibility, adaptive equipment

Developmental disability services, special education, Medicaid, food stamps, section 8 housing, vocational rehabilitation
# Charting the Life Course

## Uncharted Possibilities

Services and supports have been around for a long time. What might have been great 30 years ago, may not work for today’s vision of a quality life in the community. This tool is to help individuals and families look at a variety of kinds of supports, some of which are traditional or historic and no longer preferred by many (charted), some that are known and tried, but not necessarily the norm (slightly charted), and others that are new or unfamiliar to individuals, families and professionals, but that are more likely to lead to inclusive lives (unchartred).

<table>
<thead>
<tr>
<th>INNOVATIVE SUPPORT</th>
<th>Daily Life Employment</th>
<th>Community Living</th>
<th>Social &amp; Spirituality</th>
<th>Healthy Living</th>
<th>Safety &amp; Security</th>
<th>Citizenship &amp; Advocacy</th>
<th>Supports for Family Unit</th>
<th>Supports &amp; Services</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>UN-CHARTED SERVICES AND SUPPORT</strong></td>
<td>· Micro-enterprises</td>
<td>· Co-op</td>
<td>· Friendships</td>
<td>· Individual gym membership</td>
<td>· Limited/joint bank account, automatic bill pay, personal contract or agency agreement,</td>
<td>· Voting</td>
<td>· Social Media</td>
<td>· Exchange networks</td>
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<td></td>
<td>· Careers</td>
<td>· Adapted living space</td>
<td>· Dating/relationships</td>
<td>· Community Health Centers</td>
<td>· Personal safety devices</td>
<td>· Neighborhood group or organization</td>
<td>· Technology</td>
<td>· Time banks</td>
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<tr>
<td></td>
<td>· Competitive employment</td>
<td>· Environmental technology</td>
<td>· Parks and Recreation</td>
<td>· Health fairs</td>
<td></td>
<td>· Self-Advocacy</td>
<td>· Blogs</td>
<td>· Human service co-ops</td>
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<td></td>
<td>· Inclusive college experience</td>
<td>· Shared living</td>
<td>· Inclusive faith community</td>
<td>· Family practice providers</td>
<td></td>
<td>· Visiting your legislator</td>
<td>· Family &amp; friends</td>
<td>· General education</td>
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<td></td>
<td>· Public transportation</td>
<td></td>
<td>· Service/social club/groups</td>
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</tr>
<tr>
<td><strong>SLIGHTLY CHARTED SERVICES AND SUPPORT</strong></td>
<td>· Supported employment</td>
<td>· Independent Supported Living (ISL)</td>
<td>· Special Olympics</td>
<td>· In-home or community based therapies</td>
<td>· Limited guardianship</td>
<td>· People First/SABE</td>
<td>· Peer Support/P2P</td>
<td>· Self-Directed Supports</td>
</tr>
<tr>
<td></td>
<td>· Work crews or enclaves</td>
<td>· Home of Your Own (program)</td>
<td>· Social passes</td>
<td>· Family member or school staff implement therapy</td>
<td>· Remote monitoring</td>
<td>· Disability Rights Day at the Capitol</td>
<td>· Face-to-face local support groups</td>
<td>· $5 follows the person</td>
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<tr>
<td></td>
<td>· Job coaches</td>
<td>· Independent Living Center</td>
<td>· Social skills classes</td>
<td>· Special Olympics</td>
<td>· Special Needs Trust</td>
<td>· Project STIR</td>
<td>· Online Support Groups</td>
<td>· Technology/remote monitoring</td>
</tr>
<tr>
<td></td>
<td>· Volunteering</td>
<td></td>
<td></td>
<td>· Healthy Communities</td>
<td>· Power of Attorney</td>
<td></td>
<td>· Sib-shops</td>
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<tr>
<td></td>
<td>· Special college programs</td>
<td></td>
<td></td>
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<tr>
<td><strong>CHARTED SERVICES AND SUPPORT</strong></td>
<td>· Sheltered workshops</td>
<td>· Institutions</td>
<td>· Separate or special church service</td>
<td>· Center-based therapies (PT, OT, Speech, etc)</td>
<td>· Full guardianship</td>
<td>· Paid advocate or having someone else advocate on your behalf</td>
<td>· Institution or center based support group</td>
<td>· Systems supports</td>
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<tr>
<td></td>
<td>· Day habilitation</td>
<td>· Intermediate Care Facility (ICF)</td>
<td>· Special group outings &amp; activities</td>
<td>· Special or institutional medical care</td>
<td>· 24 hour supervision</td>
<td></td>
<td>· Provider and agency staff</td>
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<td></td>
<td></td>
<td>· Group Homes</td>
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MAY 2014

COMMUNITY OF PRACTICE FOR SUPPORTING FAMILIES OF INDIVIDUALS WITH I/DD | SUPPORTSTOFAMILIES.ORG
Our approach

- Can we change the culture of our service system from one that provides programs to one that supports families?

- Can we begin by thinking creatively about policy and systems change?

- Can we think about innovation rather than expanding the current service system model?
102,636 Tennesseans estimated to have a developmental disability*

85% (87,319)

7%

8%

Not receiving services

On waiting list for DIDD services

Receiving DIDD services**

*Based on a TN population of 6,495,978, and a 1.58 developmental disabilities prevalence rate; **Does not include Family Support program, CHOICES program.
Real Lives, Real People

Community
Family
Person

Disability Services

Community
Family
Social Services
Person with Disability
Learning from Families’ Success

- What lessons can we learn from families who are not receiving formal services, but supporting their family member with I/DD to live successful lives in their communities?
How can we improve support to ALL families?

- Redefine concept of “supports” - what are they, who receives them, and how do they contribute to achievement of important life outcomes?

- Redefine “policies and systems” so they support achievement of important life outcomes and pursuit of life aspirations

- Supports should always contribute to the quality of life for people with disabilities and their families
How do we make services more effective, less intrusive?

- A “hybrid” approach may be best: accessing both disability services and natural supports throughout the lifespan
CREATING A VISION ...
People with I/DD and their families...

- Will have access to **resources and supports across the lifespan**, that are person- and family-centered and directed, that enhance individual lives and maintain the family well-being.

- Will have opportunities throughout their lifespan to participate as **full citizens in their community**.

- Will support each other through sharing their unique experiences and knowledge to increase community belonging.
New Vision for Supports?

<table>
<thead>
<tr>
<th>DISCOVERY AND NAVIGATION</th>
<th>PEER SUPPORT NETWORKS</th>
<th>DAY-TO-DAY NEEDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information and Training Supports</td>
<td>Emotional Supports</td>
<td>Supports for Daily Care</td>
</tr>
</tbody>
</table>
### Supporting Individuals and Families Across the Lifespan

<table>
<thead>
<tr>
<th>Information and Training Supports: Knowledge and Skills</th>
<th>Emotional Supports: Mental Health and Self-efficacy</th>
<th>Instrumental Supports: Day-to-Day Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Information on disability</td>
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<tr>
<td>• Knowledge about best practices and values</td>
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<tr>
<td>• Skills to navigate and access services</td>
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<tr>
<td>• Ability to advocate for services and policy change</td>
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</tbody>
</table>
### Emotional Supports:
*Mental Health and Self-efficacy*
- Parent-to-Parent Support
- Self-Advocacy
- Family Organizations
- Sib-shops
- Support Groups
- Professional Counseling
- Non-disability community support

### Information and Training Supports:
*Knowledge and Skills*

### Instrumental Supports:
*Day-to-Day Needs*
Supporting Individuals and Families Across the Lifespan

Information and Training Supports:
Knowledge and Skills

Emotional Supports:
Mental Health and Self-efficacy

Instrumental Supports:
Day-to-Day Needs

- Self/Family-Directed services
- Transportation
- Respite/Childcare
- Adaptive equipment
- Home modifications
- Financial assistance
- Short/Long-term planning
Broadening our view

- Typically, the disability service system only addresses one piece of this framework:
  - **Day-to-Day Needs / Instrumental supports**

- How can we ensure families have access to all 3 types of supports throughout the lifespan to ensure they have the capacity to care for their family member with I/DD?
Summary of a few key concepts …

Service system should shift focus to supporting families who care for family members with I/DD

Crisis intervention is important … but helping families with planning for the future to avoid crises is also critical.

Coordinate supports and services throughout the individual’s entire lifespan.

Individuals / families should participate in evaluating & planning services.

Assist families to become engaged in helping other families.

Provide training to community organizations so that they can be more effective in providing needed
Our Progress So Far: Year 1

- DIDD Waiting List/Intake Changes
  - Laura Doutre, Dept. of Intellectual and Developmental Disabilities

- Information and Dissemination Efforts
  - Emma Shouse, Council on Developmental Disabilities
Weaving Supporting Families concepts into DIDD procedures and practices

- DIDD “front door”

- Focus the role of case managers who assist families/individuals on the waiting list on providing meaningful supports to families

- Building on community resources
Spreading the word …

- New monthly email highlighting Supporting Families concepts
  - Also using as a way to get stories & feedback from families – building a two-way street of sharing and receiving info
Spreading the word …

- Special issue of *Breaking Ground* magazine
  - Articles include …
    - Mental health tips for caregivers
    - Information and stories about parenting with a disability
    - Parent/family mentoring programs
    - Multicultural/immigrant perspectives on parenting a child with a disability
  - Much more!
Spreading the word …

- Resource folder for families
- Categories of resources include:
  - Healthy Living
  - Community Living (housing, transportation, etc.)
  - Employment
  - Education
  - Advocacy
  - Arts and Recreation
  - Independent Living
  - “Supports for families”
Spreading the word …

- Purpose and plan of resource folder
  - Assist families in navigating the maze of services and supports
  - Promote awareness of organizations that provide info and emotional supports to families

- We invite our agency partners to help us w/dissemination efforts!
BUILDING ON STRENGTHS: FAMILIES, SERVICE SYSTEM AND COMMUNITIES
Building on Our Strengths

- What are strengths of families? The current service system? Communities in Tennessee?

- What supports are working and helping families build successful lives for their member with disabilities and the entire family unit?

- How can we as a state promote more of these types of supports that are currently working (within our landscape of limited financial resources)?
Resources

- [www.supportstofamilies.org](www.supportstofamilies.org)
- [www.tn.gov/didd](www.tn.gov/didd)
- [www.tn.gov/cdd](www.tn.gov/cdd)