



SUPPORTING FAMILIES

of individuals with intellectual & developmental disabilities

THE NATIONAL COMMUNITY OF PRACTICE • FUNDED BY THE ADMINISTRATION ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES

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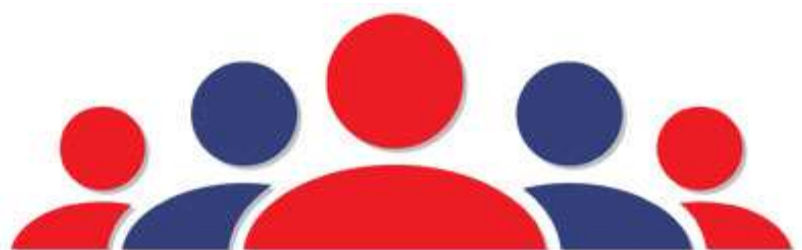
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ADMINISTRATION ON
INTELLECTUAL AND
DEVELOPMENTAL
DISABILITIES



DIDD

DEPARTMENT OF INTELLECTUAL
AND DEVELOPMENTAL DISABILITIES



TENNESSEE **COUNCIL**
on developmental disabilities

National Partners

NASDDDS



UMKC

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



SIBLING  LEADERSHIP
NETWORK

 **ASAN**
AUTISTIC SELF ADVOCACY NETWORK

 **AUCD**
ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
RESEARCH · EDUCATION · SERVICE

 National Association of
Councils on Developmental Disabilities
NACDD



SUPPORTING FAMILIES

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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

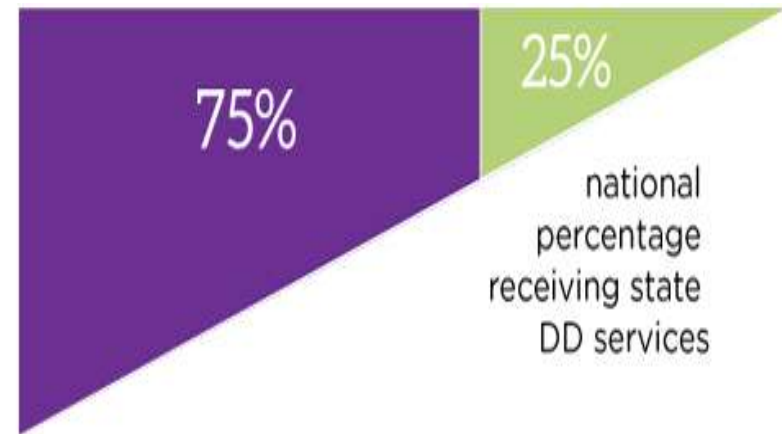
Supporting Families: A National Project

- 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?



(Based on 1.49% prevalence, US Census 2013)



(Braddock et al, State of the State 2013)





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.

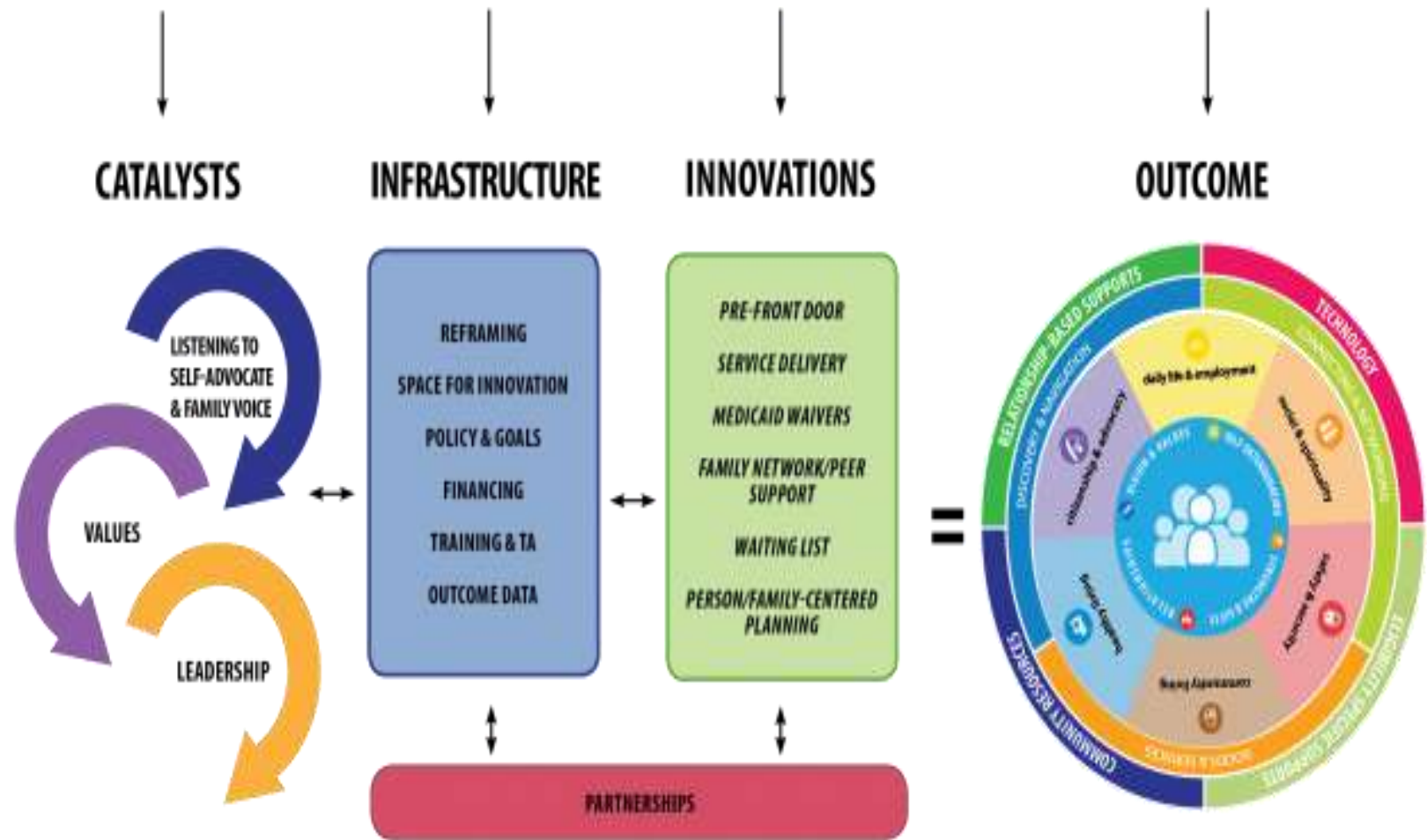


Everything is connected – What you do today affects your life in the future.



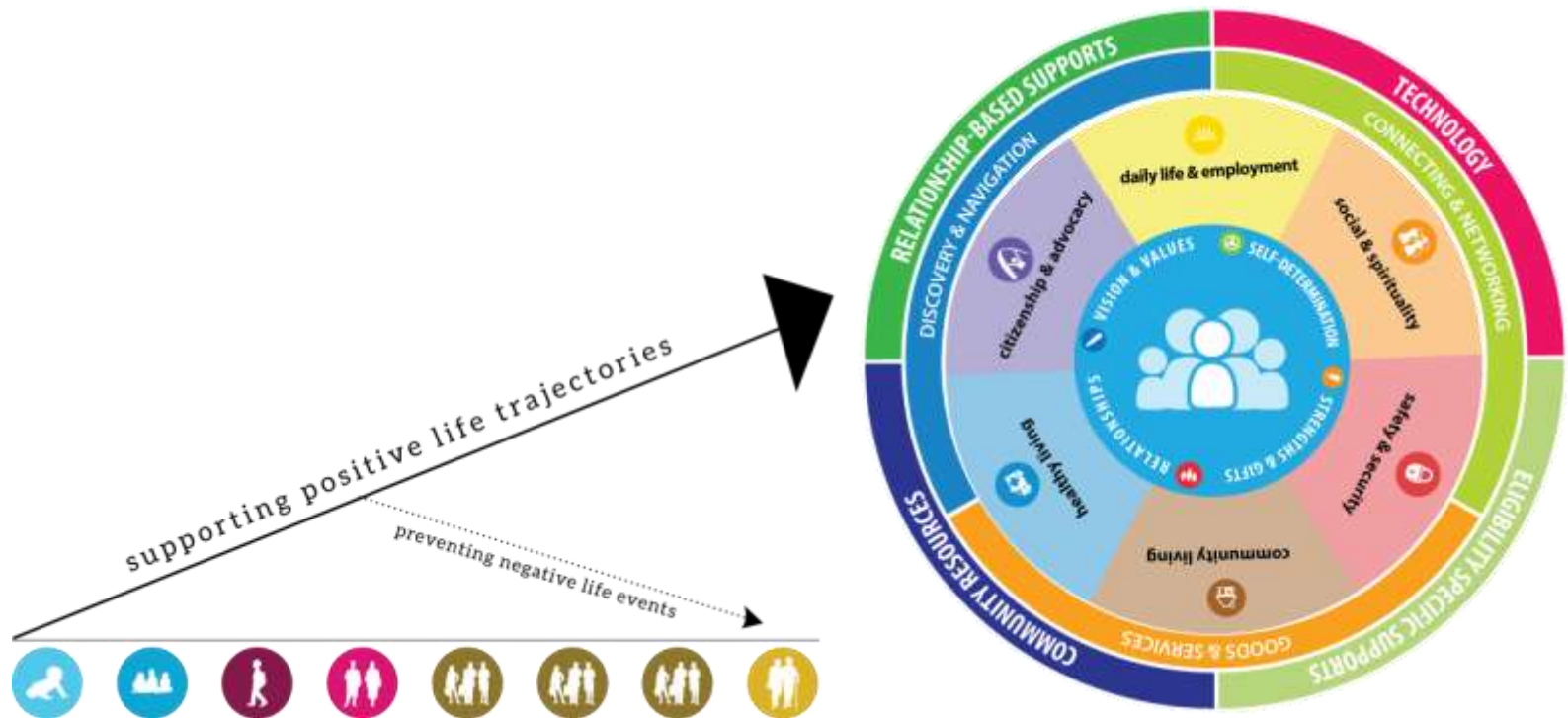
Our overall compass for people and their families “quality of life.”

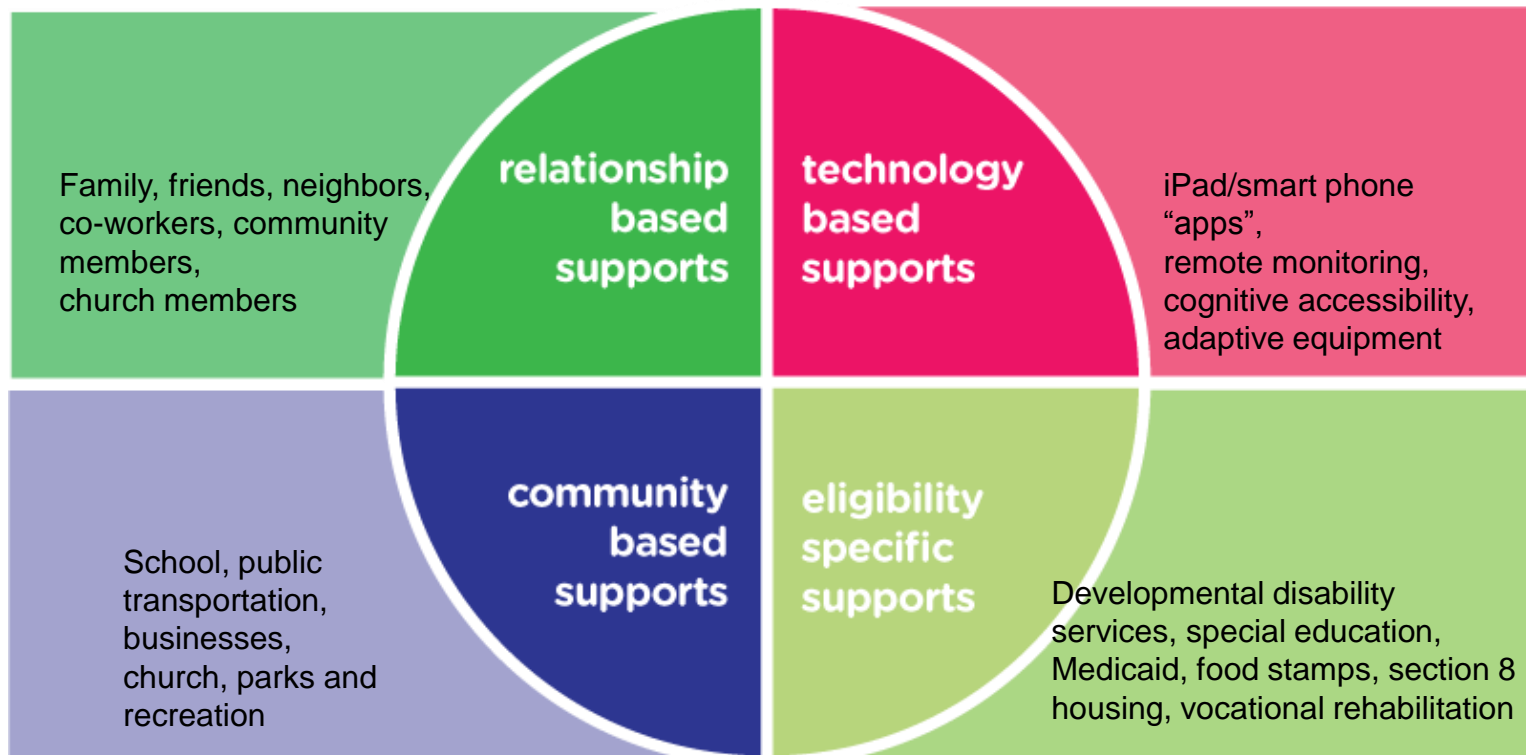
Life Course Guiding Principles



Shell Reynolds, PhD. UMKC Institute for Human Development, UCEDD. Revised June 2014. Adapted from Hall et al, 2007

Life Course Guiding Principles















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 (*uncharted*).

	 Daily Life Employment	 Community Living	 Social & Spirituality	 Healthy Living	 Safety & Security	 Citizenship & Advocacy	 Supports for Family Unit	 Supports & Services
INNOVATIVE SUPPORT	New ideas; things that someone has tried, and you replicate or adapt for your own needs; things that haven't been thought of yet or tried.							
UN-CHARTED SERVICES AND SUPPORT	<ul style="list-style-type: none"> • Micro-enterprises • Careers • Competitive employment • Inclusive college experience 	<ul style="list-style-type: none"> • Co-op • Adapted living space • Environmental technology • Shared living • Public transportation 	<ul style="list-style-type: none"> • Friendships • Dating/relationships • Parks and Recreation • Inclusive faith community • Service/social club/groups 	<ul style="list-style-type: none"> • Individual gym membership • Community Health Centers • Health fairs • Family practice providers 	<ul style="list-style-type: none"> • Limited/ joint bank account, automatic bill pay, personal contract or agency agreement, • Personal safety devices 	<ul style="list-style-type: none"> • Voting • Neighborhood group or organization • Self-Advocacy • Visiting your legislator 	<ul style="list-style-type: none"> • Social Media • Technology • Blogs • Family & friends 	<ul style="list-style-type: none"> • Exchange networks • Time banks • Human service co-ops • General education
SLIGHTLY CHARTED SERVICES AND SUPPORT	<ul style="list-style-type: none"> • Supported employment • Work crews or enclaves • Job coaches • Volunteering • Special college programs 	<ul style="list-style-type: none"> • Independent Supported Living (ISL) • Home of Your Own (program) • Independent Living Center 	<ul style="list-style-type: none"> • Special Olympics • Special passes • Social skills classes 	<ul style="list-style-type: none"> • In-home or community based therapies • Family member or school staff implement therapy • Special Olympics Healthy Communities 	<ul style="list-style-type: none"> • Limited guardianship • Remote monitoring • Special Needs Trust • Power of Attorney 	<ul style="list-style-type: none"> • People First/SABE • Disability Rights Day at the Capitol • Project STIR 	<ul style="list-style-type: none"> • Peer Support/P2P • Face-to-face local support groups • Online Support Groups • Sib-shops 	<ul style="list-style-type: none"> • Self-Directed Supports • \$\$ follows the person • Technology/remote monitoring
CHARTED SERVICES AND SUPPORT	<ul style="list-style-type: none"> • Sheltered workshops • Day habilitation 	<ul style="list-style-type: none"> • Institutions • Intermediate Care Facility (ICF) • Group Homes 	<ul style="list-style-type: none"> • Separate or special church service • Special group outings & activities 	<ul style="list-style-type: none"> • Center-based therapies (PT, OT, Speech, etc) • Special or institutional medical care 	<ul style="list-style-type: none"> • Full guardianship • 24 hour supervision 	<ul style="list-style-type: none"> • Paid advocate or having someone else advocate on your behalf 	<ul style="list-style-type: none"> • Institution or center based support group • Intensive all-day parent training • Disability specific groups 	<ul style="list-style-type: none"> • Systems supports • Provider and agency staff



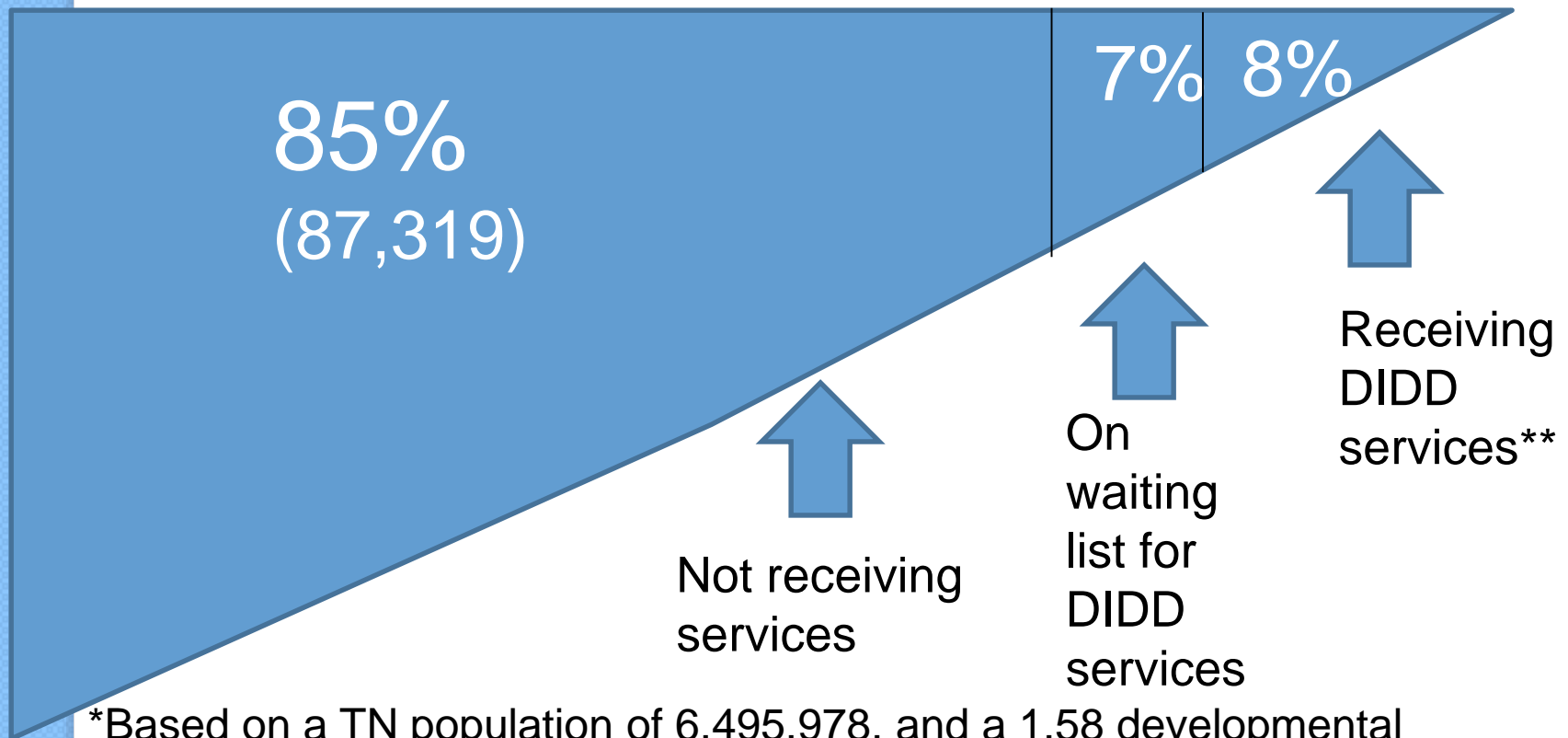
Our approach



- 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?

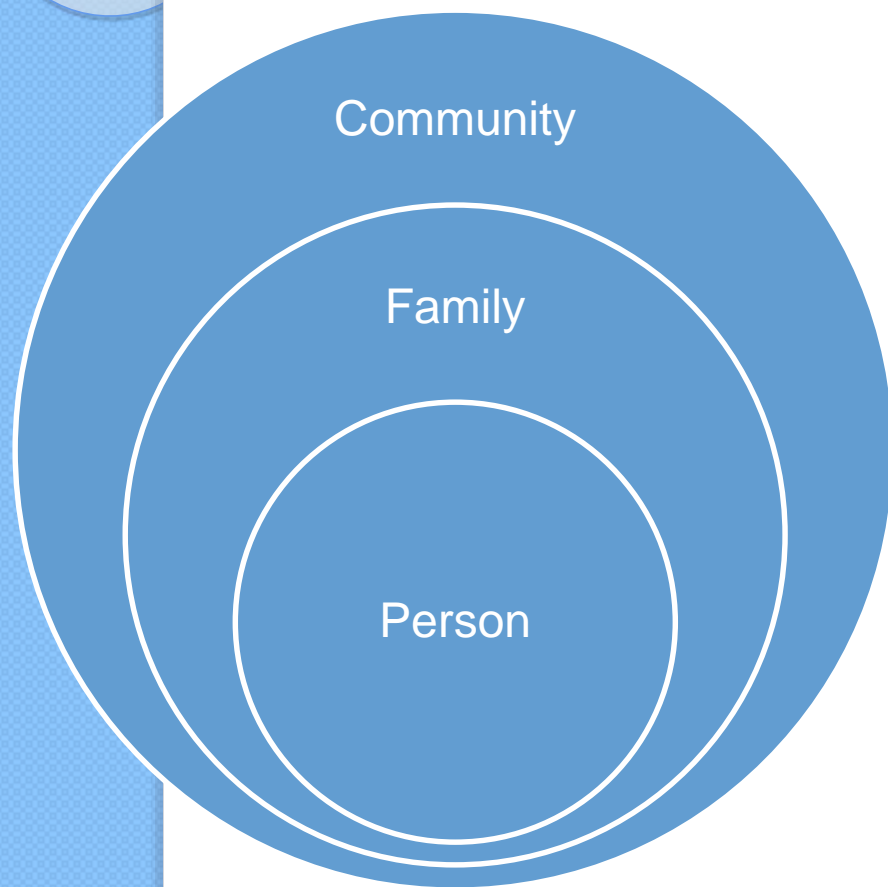
Tennesseans with disabilities

102,636 Tennesseans estimated to have a developmental disability*



*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



Disability Services



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

New Vision for Supports?

DISCOVERY AND NAVIGATION

Information and
Training Supports

PEER SUPPORT NETWORKS

Emotional Supports

DAY-TO-DAY NEEDS

Supports for Daily Care

Supporting Individuals and Families Across the Lifespan

Information and Training Supports: *Knowledge and Skills*

- Information on disability
- Knowledge about best practices and values
- Skills to navigate and access services
- Ability to advocate for services and policy change

Emotional Supports: *Mental Health and Self-efficacy*

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*

- Parent-to-Parent Support
- Self-Advocacy Organizations
- Family Organizations
- Sib-shops
- Support Groups
- Professional Counseling
- Non-disability community support

**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

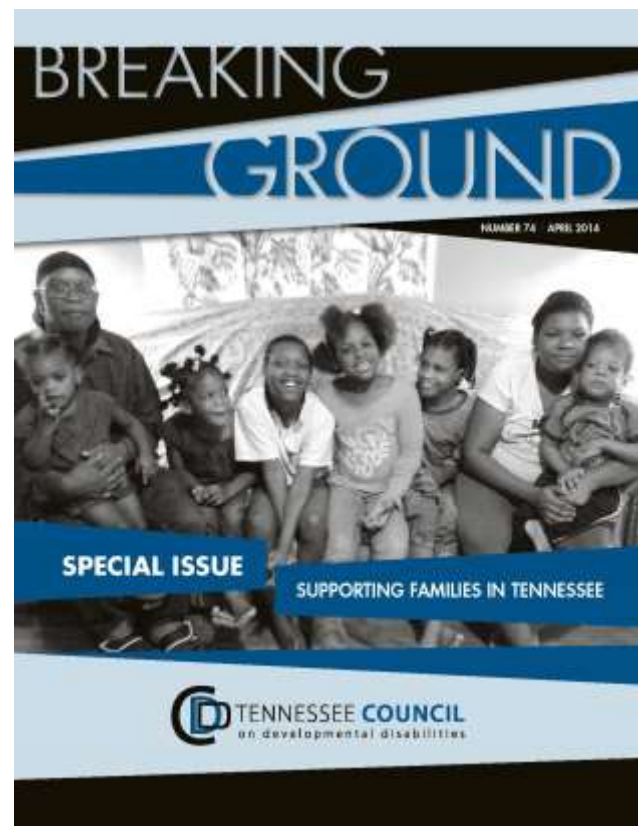
Spreading the word ...

- 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



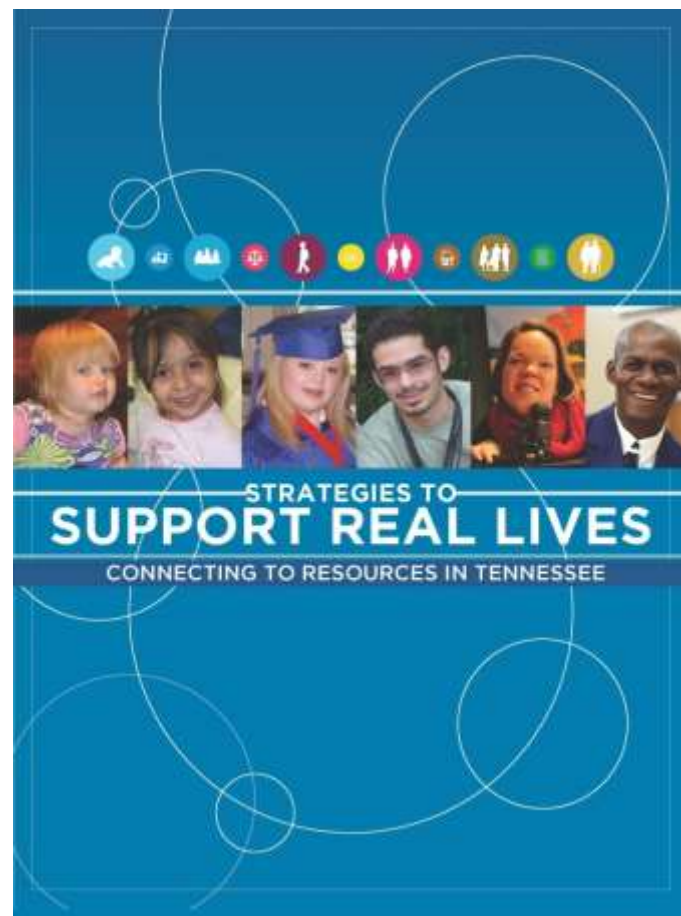
Spreading the word ...

- 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!



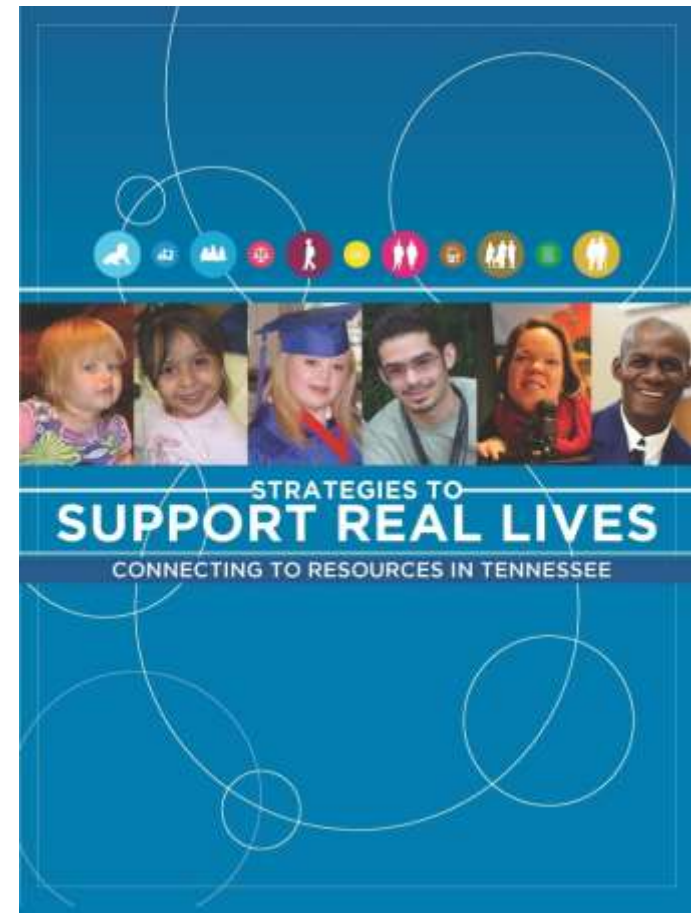
Spreading the word ...

- 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.tn.gov/didd
- www.tn.gov/cdd