



Council on  
Developmental Disabilities

# What Families Should Know about the Council

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# About Us ...

- Wanda

- Council Executive Director
- Started out in special education, school psychology
- Worked for the TN Council for 30+ years



- Emma

- Council Communications Director
- Council lead for TN's Supporting Families initiative, TN Adult Brothers and Sisters sibling support network
- Sister to a young adult with autism



# What We'll Cover Today



# Our role & our work in TN

- A state agency in the Executive branch
- Dedicated to improving policies and practices that affect the lives of Tennesseans with developmental disabilities
- We do this by:
  - Listening to priorities of Tennesseans
  - Following current best practices in the disability field
  - Informing and educating policymakers and the public
  - Launching projects that make a difference

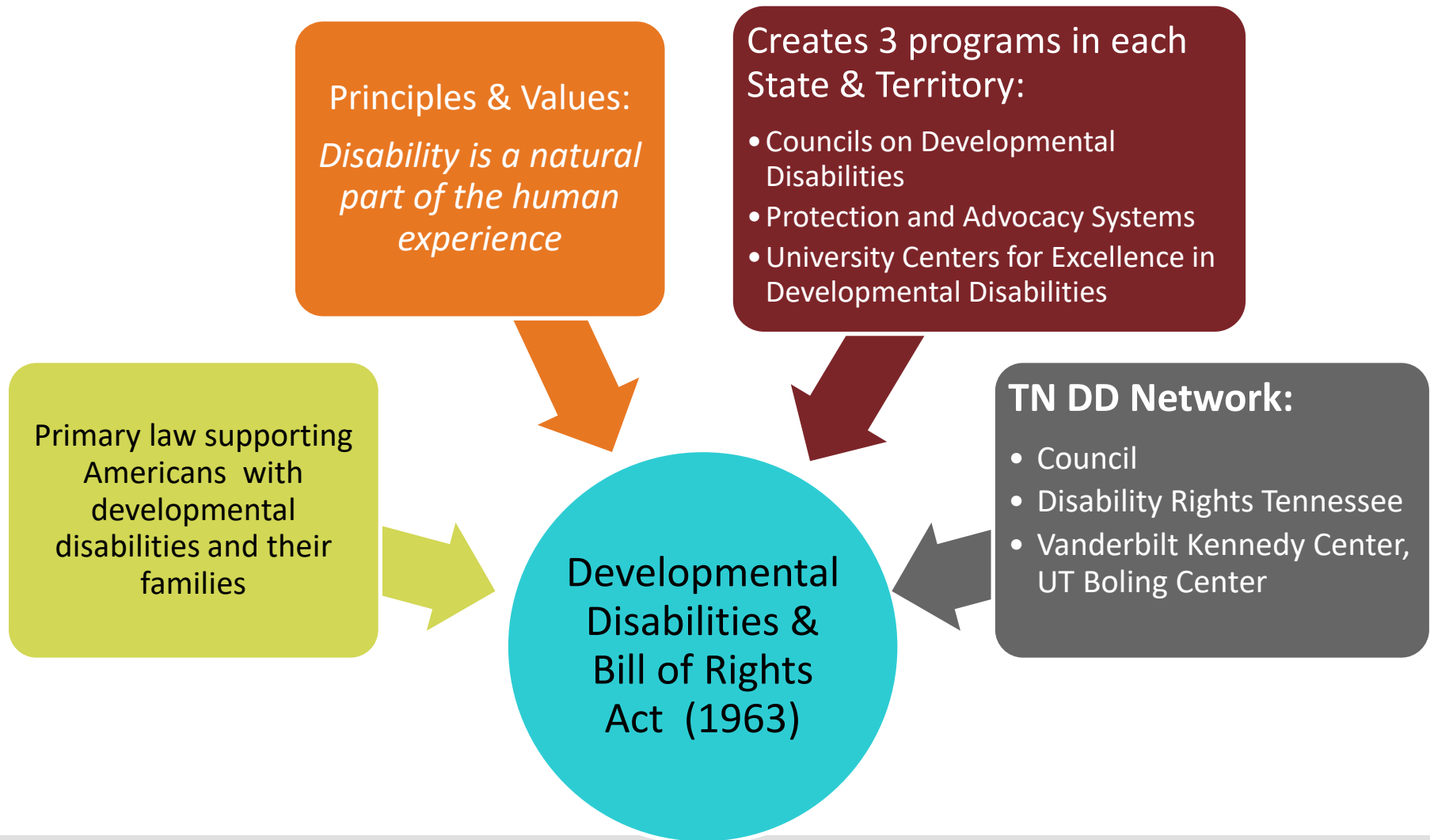
# Who we are



# Who Serves on the Council

- **Private citizens** who have a disability or a family member with a disability
  - Represent all geographic areas of the state, all disabilities across the lifespan
- Representatives from **state agencies** that provide disability-related support services across the lifespan
  - Dept. of Intellectual and Developmental Disabilities
  - Dept. of Mental Health
  - Dept. of Education
  - Division of Maternal and Child Health
  - Commission on Children and Youth
  - TennCare
  - TN Housing Development Agency
  - Vocational Rehabilitation Services
  - Commission on Aging and Disability
- **TN Developmental Disabilities Network** (*see next slide*)

# What establishes the Council?





# What the DD Act Charges Councils to Do

## Councils on Developmental Disabilities are...

... Federally funded, self-governing organizations that identify the most pressing needs of people with developmental disabilities in their state or territory.

... Positioned to take a “big picture” approach to create structural change with long term impact -- not provide direct services.

... Committed to advancing public policy and systems change that help these individuals gain more control over their lives.







**Key initiatives,  
current goals**

# Examples of TN Council Impact ...

- The Council is responsible for initiating these groundbreaking programs in Tennessee ...



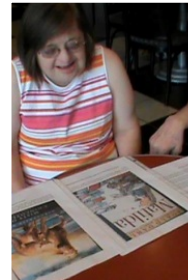
Child Care Resource and Referral Centers to provide technical assistance to child care providers



Inclusive higher education programs on college campuses



Home ownership program, visitability initiative



Next Chapter Book Clubs

# Examples of TN Council Impact ...

- The Council is responsible for initiating these groundbreaking programs in Tennessee ...



First state office of People First of TN



Nashville's first Center for Independent Living (now Empower TN)



Leadership Academy for Excellence in Disability Services



Statewide sibling support organization , TN Adult Brothers and Sisters

# How do we decide what to focus on?

- 5 year plan submitted to & approved by our federal agency
  - **Administration on Intellectual and Developmental Disabilities**
- Includes:
  - Review & analysis of state disability services
  - Stakeholder input
  - Goals for next 5 years
  - Updated/amended annually
- Most recent cycle: Oct. 1, 2016 - Sept. 30, 2021



# Current State Plan Goals



Developing Leaders



Impacting Policy and Practice



Informing and Educating Stakeholders



**Council Programs &  
Resources You Should  
Know About**

# Partners in Policymaking Leadership Institute

- Free disability leadership and advocacy training program for:
  - adults with disabilities
  - family members of individuals with disabilities of any age
- 7 Friday-Saturday sessions, Sept.-April
- No cost besides your time!
  - Sleeping rooms, meals included
  - Reimbursement for mileage
    - Reimbursement available for personal assistant, respite care if needed





# Council Scholarship Fund

- For individuals with disabilities and families
  - Assists you to attend disability conferences, trainings, or leadership meetings anywhere in TN or continental U.S.
  - Funds reimburse individuals/families for travel, child/respite care, registration, meals, lodging, etc.
- For organizations
  - Fund speakers on disability-related topics
  - Provide stipends to self-advocates, families to attend an event
- Can support opportunities, initiatives aligned with our goals
  - Leadership development
  - Impacting policy & practices
  - Informing & educating stakeholders

# Trainings & Presentations

- Staff can deliver free presentations to your community
- Topics include ...
  - About the Council & our programs
  - Disability awareness & sensitivity
  - Supported Decision Making
  - LifeCourse future planning tools
  - Disability & public policy
  - Person-centered supports
  - Self-advocacy skills & speaking up
  - Youth Readiness Days (for high school youth, at request of school systems)
  - Building Strong Brains: Adverse Childhood Experiences



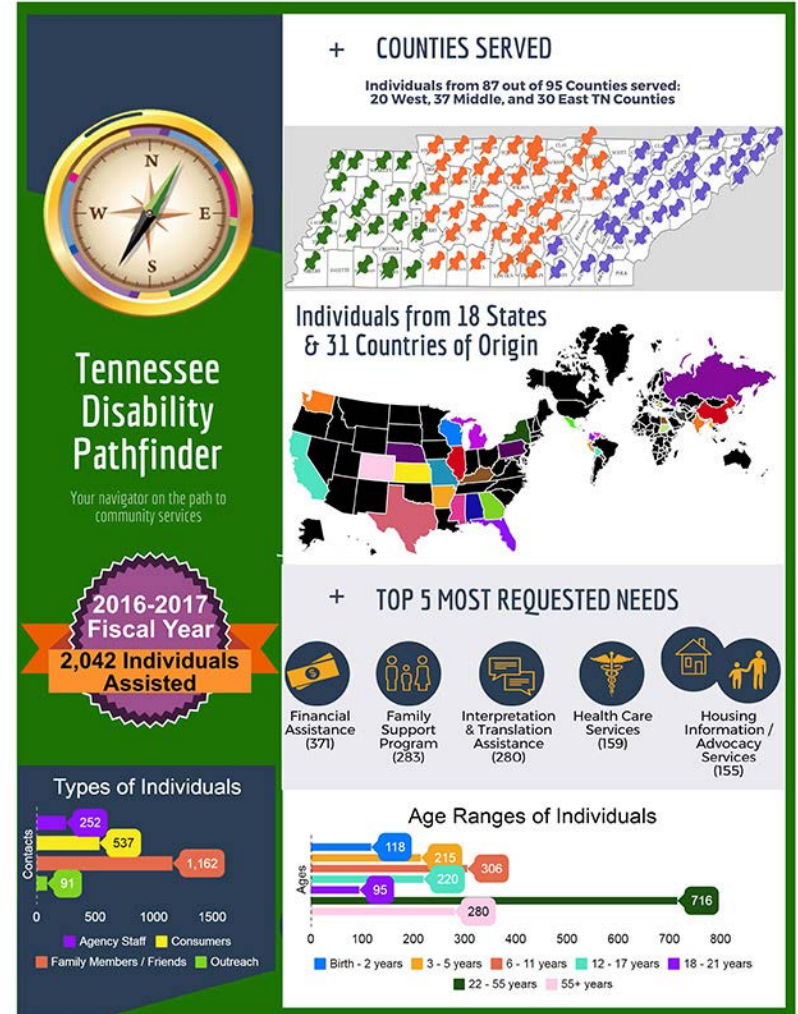
# Council Communications

- Breaking Ground magazine
  - 4-5 issues each year
  - Available by print & email
  - Can send multiple copies to schools, agencies, etc.!
- Weekly e-news
  - Council & TN disability news
  - State & federal disability policy issues
- Social media
  - **Facebook:**  
[facebook.com/TNCouncilonDD](https://www.facebook.com/TNCouncilonDD)
  - **Twitter:** @TNCouncilDD
  - **Youtube:** search “TN Council on Developmental Disabilities”



# Tennessee Disability Pathfinder

- A statewide, multilingual clearinghouse of disability resources that includes:
  - Call center
  - Searchable online disability resources database
  - General disability resource library
  - Multicultural Outreach Program
  - Community Training Program
- Launched in the '90s & still supported by the Council and Vanderbilt Kennedy Center





**When to call on us**

# When to call on the Council

- You or someone you know needs services and doesn't know where to go
- You or your family member wants to connect with other individuals, families
- You want to learn about the disability "system"
- Your organization, school, faith community, etc. could benefit from disability training
- You see a persistent barrier in your community and don't know where to go for systemic solutions



**Best Practice Initiatives:  
Supported  
Decision Making**



# Supported Decision Making & the Council

- 2016 - Began working on policy changes & education around supported decision making
- Workgroup meets regularly & includes:
  - The Council
  - STEP-TN
  - The Arc TN
  - Family Voices of TN/TN Disability Coalition
  - Disability Rights TN
  - Statewide Independent Living Council of TN
  - Vanderbilt Kennedy Center
- 2017-18 - SDM legislation passed & we've delivered 50+ trainings to lawyers, educators, families, youth, providers, support coordinators, state agencies, social workers, etc.
- Now - working on supporting individuals to develop SDM agreements



# What IS Supported Decision Making?

- Helping the person make as many decisions as possible
- Identifying which decisions need formal support, rather than taking over all decisions
- Learning about an array of options, but always starting with the least-restrictive

# Examples

From least restrictive to most restrictive

- **Informal support:** advice, consultation, discussions (*the way you and I use help with decisions*)
- **Circles of Support, person-centered plans:** informal advice, but with a team and at regularly scheduled meetings
- **More formal support that is legally documented, but without a court process:**
  - Powers of Attorney over finances, health care
  - Advance Directive for emergencies, end of life planning
- **Limited Conservatorship\***
- **Full Conservatorship\***

\*SDM can and should be *part of* conservatorship – the person should make as many decisions (big and small) as possible.

# Why supported decision making?

Currently, laws and practices throughout the country emphasize conservatorship for people with disabilities and others who need help making decisions.

## Quick statistics\*:

- Number of guardianships in U.S. has tripled since 1995
- Research indicates that most common new “ward” is 18 year old with intellectual disability
- Leading referral source to conservatorship is schools

\*Source: Jonathan Martinis, Burton Blatt Institute

# The bottom line

Conservatorship is **one** tool in a large toolbox, and we must make sure Tennesseans are educated about others. We want families to think carefully about these types of options before choosing conservatorship when their child turns 18.





**Best Practice Initiatives:  
Supporting Families  
through Lifecourse  
Framework, Tools**

# Supporting Families Community of Practice

- Administration on Intellectual and Developmental Disabilities grant [2013-2017]
  - 17+ states involved
- Led by each state's DD service system agency and DD Council
  - In TN:
    - TN Council on Developmental Disabilities
    - Dept. of Intellectual & Developmental Disabilities





# Our Goal: A Good Life for All

- Overall Goal of 'Supporting Families':
  - Maximize capacity, strengths and abilities of families so they are able to nurture and support all family members, including the person with a disability, to lead meaningful lives in their communities
  - Core Belief: **All people and their families have the right to live, love, work, play and pursue their life aspirations in their community.**

*Building a National Agenda for Supporting Families with a Member with Intellectual & Developmental Disabilities, **The Johnson Foundation at Wingspread and the Administration on Developmental Disabilities, [www.supportstofamilies.org](http://www.supportstofamilies.org), 2011.***

# Example of LifeCourse Principle: Types of Supports Families Need



**Information and Training –**  
Knowledge & Skills, Learning to Navigate Systems & Community

**Emotional Supports –**  
Mental Health and Peer Supports, Connecting & Networking

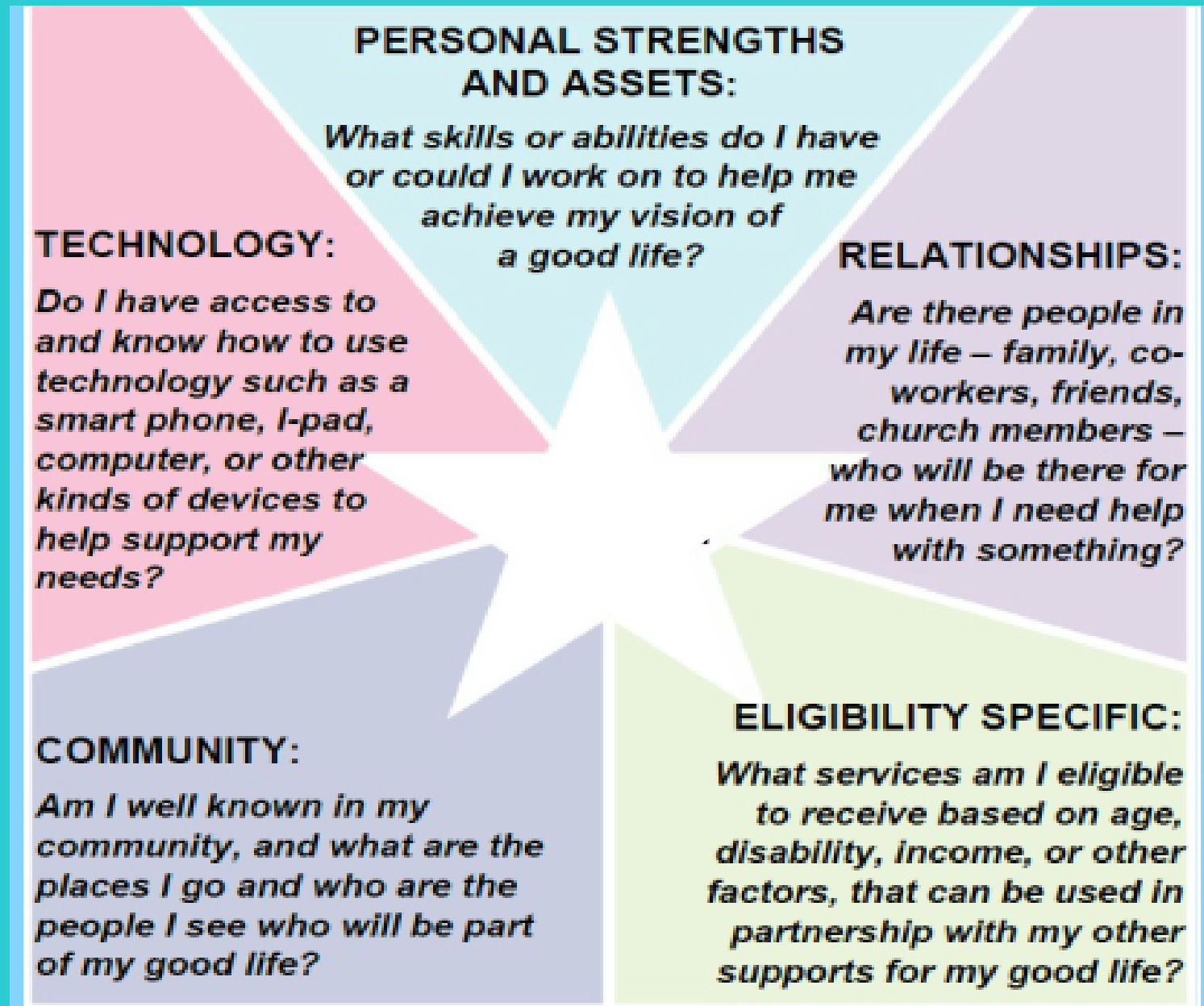
**Supports for Daily Care –**  
Services & Supports that Meet a Person / Family's Day to Day Needs

# LifeCourse Toolkit

- Created **by families for families**
- Can be used by individuals & families, educators, providers, DSPs, etc. – anyone!
- Guide conversations with self-advocates, families, planning teams
- Brainstorm and strategize about supports and how to find/develop them
- Plan future goals and life stages



# LifeCourse Tool Example: Integrated Supports Star



# Questions?

## Learn More and Stay Connected ...

Twitter: [@TNCouncilDD](https://twitter.com/TNCouncilDD)

FB: [facebook.com/TNCouncilonDD](https://facebook.com/TNCouncilonDD)

## **At [tn.gov/cdd](https://tn.gov/cdd), you can ...**

- Subscribe to our weekly Council news, weekly disability policy updates, & *Breaking Ground* magazine
  - Request trainings & presentations
- Apply to Partners or the Scholarship Fund
- Learn more about past Council initiatives