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

- Supporting Families Lifecourse Toolkit
- Supporting Decision Making
- Council on Developmental Disabilities
- Notable initiatives, current goals
- Programs & resources to know about
- When to call on us
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 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?

Principles & Values:
*Disability is a natural part of the human experience*

Primary law supporting Americans with developmental disabilities and their families

Creates 3 programs in each State & Territory:
- Councils on Developmental Disabilities
- Protection and Advocacy Systems
- University Centers for Excellence in Developmental Disabilities

TN DD Network:
- Council
- Disability Rights Tennessee
- Vanderbilt Kennedy Center, UT Boling Center

Developmental Disabilities & Bill of Rights Act (1963)
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
The Council is responsible for initiating these groundbreaking programs in Tennessee ...

- First state office of People First of TN
- Leadership Academy for Excellence in Disability Services
- Nashville’s first Center for Independent Living (now Empower TN)
- 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
  - **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.

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

PERSONAL STRENGTHS AND ASSETS:
What skills or abilities do I have or could I work on to help me achieve my vision of a good life?

TECHNOLOGY:
Do I have access to and know how to use technology such as a smartphone, I-pad, computer, or other kinds of devices to help support my needs?

RELATIONSHIPS:
Are there people in my life – family, co-workers, friends, church members – who will be there for me when I need help with something?

COMMUNITY:
Am I well known in my community, and what are the places I go and who are the people I see who will be part of my good life?

ELIGIBILITY SPECIFIC:
What services am I eligible to receive based on age, disability, income, or other factors, that can be used in partnership with my other supports for my good life?
Learn More and Stay Connected ...

Twitter: @TNCouncilDD
FB: facebook.com/TNCouncilonDD

At 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