Council on Developmental Disabilities

DISABILITY RIGHTS TN

The Arc Tennessee

The Pivot from Policy Change to Information Dissemination: Changing the Culture One Meeting at a Time

LESSONS LEARNED FROM TENNESSEE

Introductions

Lauren Pearcy, Public Policy Director, TN Council on Developmen Disabilities

Carrie Hobbs Guiden, Executive Director, The Arc Tennessee

Susan Mee, Legal Director, Disability Rights Tennessee

Session Overview

This workshop will provide an overview of the **key lessons learned** in Tennessee related to:

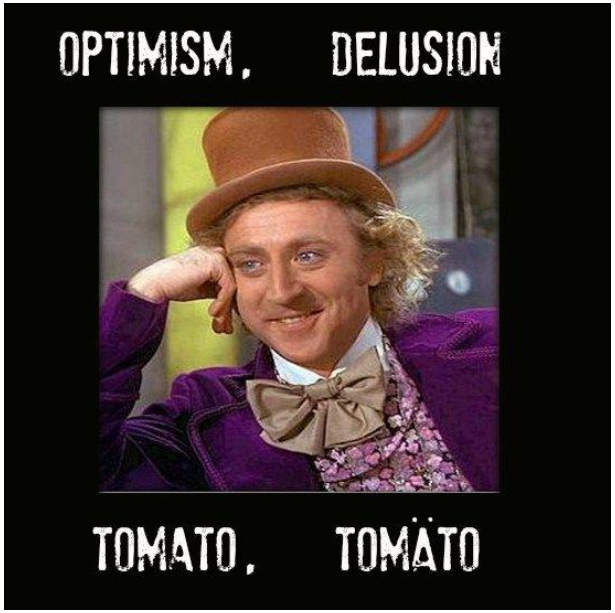
- Awareness about supported decision-making as an option for Tennesseans with disabilities
- Legislation
- In-person meetings to share, gather info across the state
- New messaging around supported decision-making
- Next up: Supporting people in actually using supported decision-making

Where we started

- In Tennessee, our journey has required us to **listen and adapt** rather than pursue a “straight” path for implementing SDM as a formal option for Tennesseans with disabilities.

Where we started

- Back in 2016, helped introduce legislation that would establish an SDM agreement form and legal parameters for its use, modeled after a successful bill in Texas.



The journey

- The debate about the bill became so controversial that the four-page bill was only one sentence by the time it passed.

The legislation

- Originally, the bill was pitched as a “Supported Decision Making Agreement Act,” which included much prescriptive language, including what the form would look like:

SUPPORTED DECISION-MAKING AGREEMENT

Appointment of Supporter

I, (insert your name), make this agreement of my own free will.

I agree and designate that:

Name:

Address:

Phone Number:

E-mail Address:

is my supporter. My supporter may help me with making everyday life decisions relating to the following:

Y/N Making educational decisions;

Y/N Making financial decisions;

The legislation

Stakeholder groups "came out of the woodwork"

- Bankers association
- Nursing facilities
- The Bar Association
- Administrative Office of the Courts (judges)

Image shows a full committee room when the bill was heard, including people with disabilities but also lobbyists who do not normally hear about disability issues.

The legislation

- Spurred excellent discussions, relationships built
- Our understanding of SDM was evolving as we were trying to "sell" it
- Our messaging ("SDM as an alternative to conservatorship") was alienating key stakeholders

Lesson learned: Take the long-term view, let "plans" derail, change as long as the most fundamental goal is moving forward

Image of Jonathan Martinis, Burton Blatt Institute, testifying before the TN Senate Judiciary Committee

The ultimate goal

Knowing the ultimate goal is a must. This guides what you are willing to compromise on and adjust along the way.

- Ours: **Protecting the rights of people with disabilities to make as many of their own decisions as possible.**

Baby steps

- 2018 Tennessee's new "Supported Decision Making" law:

State of Tennessee

PUBLIC CHAPTER NO. 605

SENATE BILL NO. 264

By Massey, Jackson, Bailey, Yager

Substituted for: House Bill No. 941

By Carter, Jernigan, Pitts, Hardaway, Hawk, Ragan, Daniel, Faison, Powell, Byrd, Forgety, Vaughan, Moody, Favors, Gant

AN ACT to amend Tennessee Code Annotated, Title 34, relative to supported decision-making agreements.

BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF TENNESSEE:

SECTION 1. Tennessee Code Annotated, Section 34-1-101, is amended by adding the following as a new subdivision:

( ) "Least restrictive alternatives" means techniques and processes that preserve as many decision-making rights as practical under the particular circumstances for the person with a disability.

SECTION 2. This act shall take effect upon becoming a law, the public welfare requiring it.

Baby steps

Added to the definition section of the guardianship statute:

"'Least restrictive alternatives' means techniques and processes that preserve as many decision-making rights as practical under the particular circumstances for the person with a disability."

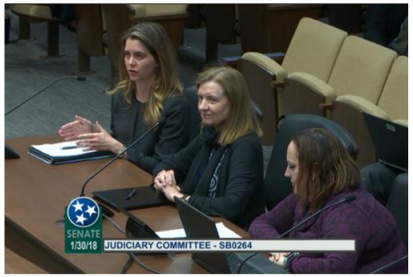
Baby steps

We still celebrated.

TN Council on Developmental Disabilities

SUPPORTED DECISION MAKING

ON APRIL 2, 2018, GOV. BILL HASLAM SIGNED SB264/HB941, TENNESSEE'S SUPPORTED DECISION MAKING LEGISLATION.



We are proud to have worked with the bill's sponsors, Sen. Becky Massey (R-Knoxville) & Rep. Mike Carter (R-Ooltewah) and a workgroup of 8 disability organizations on bringing this topic to TN.

We will continue working together to educate Tennesseans about how to use Supported Decision Making.

The pivot

- The legislative process spurred key conversations we would not have had.
- A turning point occurred during the meeting to decide the bill's fate: the judiciary's legal counsel said to us,

"The law doesn't need to change. Educate us."

- **That's when we decided to pivot from legislating change to cultivating behavior change.**

One meeting at a time

We decided the most effective action in the short-term is **wide-spread, in-person information dissemination** about what people could do NOW, simply by becoming informed about existing options and empowered to use them.

We now have more invitations than we can keep up with.

One meeting at a time

- More than 3,000 Tennesseans since 2017
- To date, more than 250 presentations (sometimes multiple in the same day)

One meeting at a time

Use our organizations' distinct expertise/networks to reach broad range of stakeholders:

- **Families and individuals** (example: "Our Place Nashville" for students enrolled in inclusive higher education; "Social Spot" church group for parents of kids who have Autism)
- **State agencies: from leadership to frontline staff** (example: training just for General Counsels featuring Jonathan Martinis; training to case managers in local areas)
- **Legal professionals** (example: Statewide annual judicial conference; statewide "Equal Justice University" for legal aid attorneys)
- **Conservatorship Association**

One meeting at a time

- **Healthcare professionals** (example: Medicaid “Provider Expos” across the state)
- **Educators** (example: parent nights at local high schools; statewide “Partners in Education” annual conference)
- **Disability organizations** (example: Disability MegaConference; local chapters of diagnosis-specific groups like Down Syndrome Association)
- **Other**: For example, TN Social Workers’ Annual Conference

Every presentation is tailored to the audience and regularly updated to reflect new insights, feedback gleaned from each meeting.

One meeting at a time

Every presentation is tailored and updated.

For example: worked with Jonathan Martinis of the Burton Blatt Institute recently to develop a tailored presentation for a broad audience of healthcare providers in the state's Medicaid network – including some who do not necessarily interact regularly with people with disabilities.

"New" content includes:

- Making decisions with a patient who has a disability
  - Including: a patient who has a conservator
- The PRACTICAL model
- Approaching the Medical Affidavit for guardianship/conservatorship petitions. "Would you testify under oath to what you're signing?"

Key Resources

Shared PowerPoint deck

- To maximize capacity, our three organizations share a training curriculum
- Triage requests to either co-present or divide/conquer.
- Train the trainer

Dedicated website

- Hosted by the Council on Developmental Disabilities with contributions from The Arc, Disability Rights TN
- Links to the National Supported Decision Making Resource Center

Website and tools for families

How do I use Supported Decision Making in my life?

- Use this LifeCourse tool for decision making (adapted from the previous 'Stoplight tool') to help identify which types of decisions you or a person with a disability may want or need help making.
  - This tool was developed by the University of Missouri (UMKC) Kansas City University Center for Excellence in Developmental Disabilities, which the Tennessee Council partnered closely with through our Supporting Families Community of Practice initiative. You can also use this LifeCourse Supports Star for Decision Making to brainstorm types of supports someone can use to help them in making choices.
- Use this booklet written in plain language, designed for self-advocates, to learn about supported decision making, developed by the Autistic Self-Advocacy Network (ASAN).
- Use this short background paper called "Setting the Wheels in Motion" for using Supported Decision Making, including step-by-step guides for self-advocates and their supporters.

See video, made by The Arc TN: https://youtu.be/jcvFzGgZbG0

Longer Term Goals

- **Understandable, practical information** to families considering conservatorship and other key players in "the pipeline" to conservatorship (lawyers, educators, etc.)
- **Support for people who want to use supported decision-making** but need help doing so
- **Structural changes to law and policy**
- **Culture change**: expectations about how people with disability make decisions and speak for themselves

Message Testing

The Council funded a professional message-testing project which Disability Rights Tennessee is conducting with a consultant about supported decision-making. The project will gather direct input from Tennesseans through a series of professionally-run focus groups targeting:

- People with disabilities and family members
- Educators and school administrators
- Legal professionals

Information gained through these focus groups will help Tennessee disability partners shape messaging on Supported Decision-Making in an effort to maintain clarity and ease on the subject.

This project began with a grant from the Supported Decision-Making National Resource Center and has been additionally funded by The Arc Tennessee, the Tennessee Council on Developmental Disabilities, and Disability Rights Tennessee.

Pilot project underway

To establish a Supported Decision Making program for adults with Intellectual and Developmental Disabilities that currently have no natural supports (family or friends) available to assist in making informed choices about their lives. Goals include:

1. Test the viability of a formal SDM service provided by a professional organization
2. Develop a process that includes fading away from formal supports toward natural supports, as appropriate
3. Identify barriers, unforeseen liabilities, and other challenges related to testing SDM

TN Council on Developmental Disabilities

The Arc Tennessee

Discussion and Q&A

Contact Information

Disability Rights Tennessee Susan Mee, Legal Director
susanm@disabilityrightstn.org

The Arc Tennessee Carrie Hobbs Guiden, Executive Director
cguiden@thearctn.org

The Council on Developmental Disabilities Lauren Pearcy, Public Policy Director, lauren.j.pearcy@tn.gov