

Enabling Connections: How You Can Build & Sustain Relationships with Elected Officials



Alecia Talbott
Down Syndrome
Association of Middle
Tennessee Executive
Director





Build & Grow YOUR Advocacy Program



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Successful Advocacy Programs

- Built with passion & are active
- Secure organization leadership excitement
- Recruit & involve families & self-advocates
- Collaborate with partners
- Make it easy to advocate
- Creative
- Flexible & patient



It Takes a Village



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Energize the Board of Directors



Excite, Empower & Activate Families



Down Syndrome Policy Network of TN (DSPNTN)



+ Invite



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Self-Advocate Involvement



Testify



Create Advocacy Partnerships & Collaborate



Make it Easy



Legislative Update & Call to Action

First some great news thanks to your strong advocacy!

[#1 Mechanical Restraint Bill HB0127](#) was defeated this week! Watch the [committee discussion here](#).

[#2 The Able Estate Recovery](#) bill was signed into law by Governor Lee! This prohibits the state from seeking **estate** recovery of funds in an **ABLE** account following the death of a beneficiary, beyond what is required by federal law.

DSAMT is already talking about legislative priorities for 2024, so look for exciting things to happen next year, too.



Here is how YOU CAN HELP!

The [Boarding School for "At Risk" Students Bill HB1214](#) would create charter "boarding schools" for kids who fall under the bill's definition of "at-risk," which includes students w/disabilities.

We need to unequivocally say that **boarding schools are not good options and are**

TN ABLE Estate Recovery Bill

ABLE accounts are tax-advantaged accounts for individuals with disabilities that allow money saving beyond the asset limit for Medicaid, so they can access additional funds without jeopardizing their services, supports or health care.



ABLE account holders are allowed to deposit up to \$17,000 per year into their accounts, and accounts may hold up to \$100,000. Currently, ABLE accounts are subject to "estate recovery," meaning that following the death of the beneficiary, TennCare can recover funds from these accounts equivalent to the cost of service provided by TennCare over the beneficiary's lifetime. This leaves the funds in ABLE account unprotected, and also has prevented many families from opening these accounts for their loved ones with disabilities.

The concerns of families have been heard, and the disability community is moving forward this legislative session with efforts to pass a law that would prohibit TennCare from accessing these accounts, lead by the Tennessee Disability Coalition and supported by DSAMT. Email Erin@somethingextra.org for more details and talking points about the bill.

The bill will be presented next week for discussion in the Senate Health and Welfare Committee. It is always critical for lawmaker to hear from constituents who may be impacted by proposed legislation. Below is the contact information for the members of this committee; we encourage you to reach out via phone (preferable) or email to one of more of these members and express your support for the ABLE Estate Recovery Bill:

- Rusty Crowe 615-741-2468 sen.rusty.crowe@capitol.tn.gov
- Bo Watson 615-741-3227 sen.bo.watson@capitol.tn.gov
- Joey Hensley 615-741-3100 sen.joey.hensley@capitol.tn.gov
- Richard Briggs 615-741-1766 sen.richard.briggs@capitol.tn.gov
- Ed Jackson 615-741-1810 sen.ed.jackson@capitol.tn.gov
- Becky Massey 615-741-1648 sen.becky.massey@capitol.tn.gov (Bill Sponsor)
- Randy McNally 615-741-6806 sen.randy.mcnally@capitol.tn.gov
- Doug Overbey 615-741-0981 sen.doug.overbey@capitol.tn.gov
- Jeff Yarbro 615-741-3291 jeff.yarbro@capitol.tn.gov

Join TN DS Policy Network



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More Samples



HB2053/SB2008, the Down Syndrome Information Act 2018

What is the Down Syndrome Information Act?

The bill requires the Tennessee Department of Public Health to make available up-to-date, accurate information about Down syndrome. The information will be available through the Department's website to any provider delivering a prenatal or postnatal diagnosis of Down syndrome or care of Down syndrome.

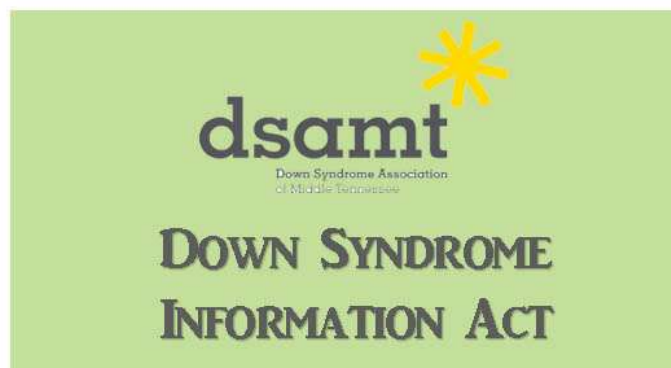
This pro-information law will ensure that health care providers give accurate, quality information to anyone receiving a prenatal or postnatal diagnosis of Down syndrome and will be comprised of the following:

- up-to-date and evidence-based written information about Down syndrome reviewed

about Down syndrome to women and families considering prenatal testing. Unfortunately, the federal law was never funded and, in the absence of funding, advocates in several states have taken up the issue with their state legislatures. As of May 2016, the following states have passed Down syndrome information bills: Delaware, Florida, Illinois, Kentucky, Louisiana, Maryland, Massachusetts, Minnesota, Missouri, Nebraska, New Jersey, Ohio, Pennsylvania, South Dakota, Texas, and Virginia.

Why is it so important to Tennesseans?

What kind of information did you receive when you were informed of your child's diagnosis of Down syndrome? What would it have meant to have your doctor give you accurate, up-to-date



DSAMT is thankful for bill sponsors, Representatives Rick Staples (D - Knoxville) and Sam Whitson (R - Franklin) and Senator Becky Massey (R - Knoxville), for their work and for the state-wide grassroots advocacy efforts, all of which led to the passing of this important bill.

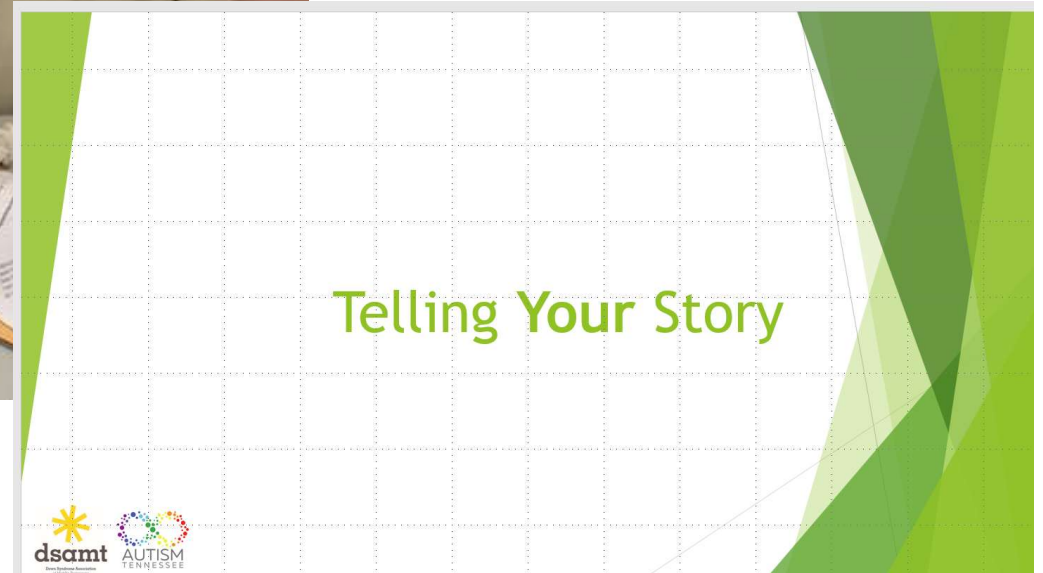
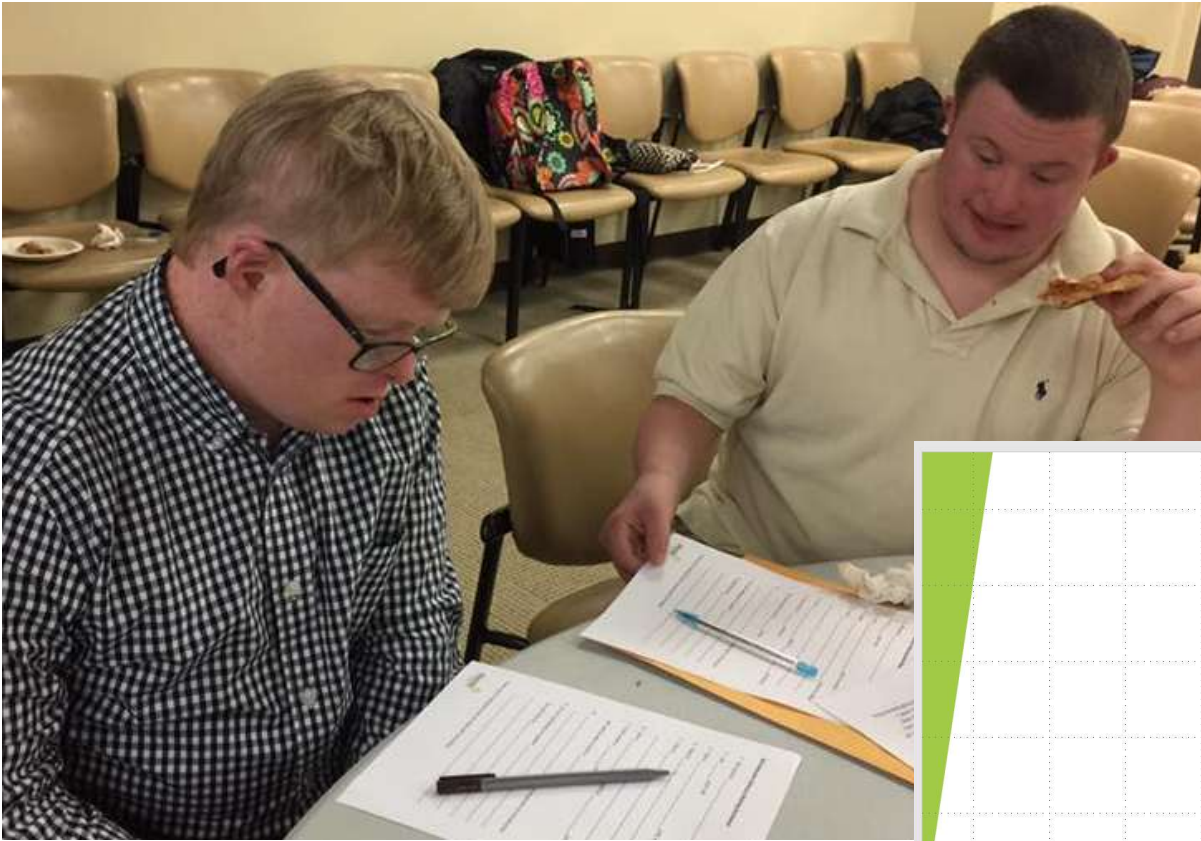
On Thursday, April 19, 2018, Governor Bill Haslam signed HB2053/SB2008, The Down Syndrome Information Information Act.

This law will help ensure that expecting and new parents in Tennessee have access to the most up-to-date, accurate information on Down syndrome and how to connect to First Call and support organizations.



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Training to Advocate Through Storytelling



Take it to the
Next Level

Join us in welcoming our *new*
Policy & Advocacy Director!

Erin Richardson



Erin's focus will be
empowering all advocates
to have an effective
voice, through trainings,
information and support.

Say hi to Erin:

Erin@somethingextra.org



Down Syndrome Association
of Middle Tennessee



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Get Creative



Leverage Legislative Relationships



Down Syndrome & Disability Day on the Hill



Down Syndrome
DAY ON THE HILL
NASHVILLE • 3-21-2019

Down Syndrome
DAY ON THE HILL

Wednesday, March 21, 2012 | Tennessee State Capitol | Nashville, TN



DSAMT and its self-advocates with Down syndrome invite all Tennessee legislators for a *complimentary grab & go breakfast* in Conference Room 8D in Cordell Hull on Down Syndrome Day on the Hill - March 21, 2019.

March 21st (3-21) is selected as Down Syndrome Day on the Hill, as it is World Down Syndrome Awareness Day, representing the third copy of the twenty-first chromosome, which causes Down syndrome.

DSAMT organizes Down Syndrome Day on the Hill to directly connect families who have a child with Down syndrome with their lawmakers, so that families and self-advocates can discuss important issues affecting individuals with Down syndrome in Tennessee.

7:45-8:45am:
DSAMT to serve breakfast to legislators in Conference Room 8D in Cordell Hull

9:00am:
House Floor Session (DS families recognized and House Resolution HJR227 declaring 3-21-19 Down Syndrome Awareness Day in TN)



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Our Stories

A collection of personal stories by individuals with Down syndrome and/or Autism describing the realities of living with a disability and the various obstacles and challenges they face.



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The Stories

<https://somethingextra.org/programs/advocacy/our-stories/>

My story **Will McMillan**
Age 33
Parents: Tom and Elise McMillan
Nashville, TN



My name is Will, and this is my story.

I am from Nashville, Tennessee. I am a self-advocate. I like reading for fun, and like spending time with my friends. I have voted in every election. I am a graduate of Pope John Paul II High School and Next Steps at Vanderbilt. I work at the District Attorney's Office.

I began walking more during the pandemic, but there are many areas where there aren't good sidewalks. It's hard to find safe places to walk. In my neighborhood where my apartment is and where my family's home is, there aren't many sidewalks. Another issue, depending on the time of day is crime.

I even found studies that show that people who live in neighborhoods with good places to walk are healthier because everyone would benefit from being a little more active- but it is especially important for those of us with Down syndrome. Without these safe places, people also must depend more on help from police, and they are already stretched very thin.

For many reasons, we should all focus on this idea of walkability. If roads are being repaired in an area, why not add sidewalks that are accessible? If companies are building new buildings, why not require them to add sidewalks that are accessible? That would help everyone. It would also be good for everyone to be more aware of their surroundings and to take classes like self-defense classes. We need to make Nashville a safer place for everyone.

Thank you for taking the time to learn about me. I'm happy to follow up and answer any questions you have. I'm also happy to provide any resources. Next time you are in my neighborhood, come take a walk with me.

Our Stories Event

Please Join Us For A
Legislator Dinner
— with the —
Down Syndrome Association
of Middle Tennessee
— and —
Autism Tennessee

Individuals and/or caregivers are creating their personal stories to share with you. You will meet them, see a video presentation of their stories and have the opportunity to discuss issues with them.

Tuesday, April 5, 2022
Reception 6:00-6:30
Dinner *and* Presentation 6:30-7:30

Sheraton Grand Nashville Downtown
623 Union Street
Nashville, TN 37219

RSVP at dsamt.regfox.com/our-stories



Down syndrome and autism: A walk in our shoes

by Dennis Ferrier | Wed, May 18th 2022, 9:55 PM CDT



Down syndrome and autism: A walk in our shoes (WZTV)




NASHVILLE, Tenn. (WZTV) — Alecia Talbott gets some work done while her 13-year-old son William Ron works on yet another painting.



Resolutions/Proclamations





Rome Wasn't Built in a Day



Thank you!

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o. 615-454-3129



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