

Advocacy Toolkit for Families with a New or Potential Diagnosis of Intellectual or Developmental Disability



This toolkit has been designed for parents or guardians of a child who has been recently diagnosed with an intellectual or developmental disability (IDD), or caregivers who may be concerned about their child's development. A group of trainees of the Vanderbilt Consortium LEND (Leadership Education in Neurodevelopmental Disabilities) Program have used their respective educational and healthcare experiences to produce this collection of frequently asked questions and helpful resources for families to promote best possible outcomes in their child's development.

➤ Section 1: Evaluation and Diagnosis

Tennessee Early Intervention System (TEIS)—What is it?

Early Intervention is available to children from birth to 3 years of age. It supports families by:

- Helping their child with a disability to grow and develop better.
- Encouraging participation of the whole family in the child's growth.

Why is Early Intervention important?

- In the first three years of life, a child's brain is still maturing and most responsive to therapy.
- It can change a child's path of brain development to improve outcomes for the future.
- It helps families to better meet their child's needs from an early age.

How does Early Intervention work?

- It takes place in a natural setting, such as at home and with the family.
- Families and professionals work together to create and monitor goals for the child.
- Goals are centered on the family with the child and family's daily routine in mind.
- Families use activity programs at home to work with their child.
- Skilled professionals provide services and training to families.

What is an IFSP?

If your child qualifies for Early Intervention after being tested, you will receive an Individualized Family Service Plan (IFSP). IFSP is the road map that explains:

- Family involvement with helping your child grow.
- What your child will receive in the early intervention.
- The goals you hope for your child to reach.



Worried about your child's development?

If you answer “**yes**” to any of these questions, your child would **likely benefit from an evaluation** to see if they can get **early intervention** services.

My child was born with a disability (e.g., Down syndrome).

Follow this website to access a “diagnosis list” for eligibility: tn.gov/didd/for-consumers/tennessee-early-intervention-system-teis/eligibility-information.html

Has your child missed any of the developmental milestones that a child at their age typically should have met?

Follow this website and click on your child's age to know what milestones they should have met: cdc.gov/ncbddd/actearly/milestones/index.html

Was your child born before the due date?

Follow this website for more information to see if your child meets guidelines for this: www.dropbox.com/s/nazxr2ax9ouvaz/TEIS_Premature_Infant_Criteria.pdf?dl=0

If you are worried about your child, don't wait. YOU know your child best.

How can my child get an evaluation with Early Intervention?

Call **(800) 852-7157** or fill out the online form at this website: stateofennessee.formstack.com/forms/teis_referral

When you complete the online form, it is sent to the TEIS office in your area.

- The TEIS office will contact you to schedule an evaluation appointment for your child.
- If you are out of state, the form will be sent to the district office in Tennessee where you and your family are moving.
- To find a TEIS office in your area, follow the link to this website and scroll to the bottom: tn.gov/didd/for-consumers/tennessee-early-intervention-system-teis.html

Are you worried about your child who is older than 3 years?

You can follow these steps to request a free evaluation through a public school:

1 Find out where to send your request for evaluation.

Ask the teacher or principal or call the district office of your school.

2 Write a formal letter.

Your request should be in writing.

3 Be specific in the letter about why you want your child to be evaluated.

Write as much as you need to write.

4 Consent to your child being evaluated.

- Clearly state you give consent for your child to be evaluated, by using the phrase, "I give consent."
- Without consent, the school cannot move forward in the process.

5 Make sure the letter arrives.

- If possible, hand-deliver the letter to be sure it gets there.
- Ask for a signature and date from the person who takes the letter to document when your request was made and to verify the start of the timeline.
- Once the school receives the letter, they must begin the process—it's the law.

6 Follow up.

- The process begins with a parent's request for an evaluation, and then the school provides an opportunity for the parent to indicate consent with the specific evaluations that will be conducted. Parents will want to make sure that the appropriate evaluations are in the works and are provided in a timely manner.
- According to the law, the school has 60 calendar days to evaluate your child.
- Call or email the school and ask for a copy of evaluation results if you have not heard back after five days following the evaluation.

What happens after the evaluation?

If the testing shows your child would benefit from additional services, an **Individualized Education Plan (IEP)** may be created for them. The school and the parents have **30 days** to draw up this IEP.

What is an IEP?

- The agreement that special education services will be provided for children and young adults between 3 and 21 years old who qualify.
- The plan describes the level of special education, supports, and services the child will get in school to help them reach their highest potential.
- It is unique to the needs of each individual student.
- School professionals and the parent(s) agree on goals for the child in the IEP.
- Professionals monitor the child's goals.
- Progress reports should be provided to the parent/guardian throughout the year.
- Periodically, the meeting is held again to update the IEP.

Follow this link to access a guide that can better prepare you for the IEP and explain the process: autismspeaks.org/tool-kit/guide-individualized-education-programs-iep



➤ Section 2: Six Laws to Know as a Parent or Guardian

1. Americans with Disabilities Act (ADA)

adata.org/factsheet/ADA-overview

The landmark civil rights law protecting the rights of Americans with disabilities, the ADA sets forward a framework for many of the related laws that provide accessibility, parity, and non-discrimination guarantees for both adults and children with disabilities.

2. School Options and Rights

tn.gov/education/finance-and-monitoring/idea.html

The Individuals with Disabilities Education Act (IDEA) is a law ensuring services to children with disabilities throughout the nation. IDEA governs how states and public agencies provide early intervention, special education, and related services to more than 6.5 million eligible infants, toddlers, children, and youth with disabilities. Infants and toddlers with disabilities (birth to 3 years) and their families receive early intervention services under IDEA, Part C. Children and youth (3 to 21 years old) receive special education and related services under IDEA, Part B.

3. Medicaid (Katie Beckett Waiver)

tn.gov/tenncare/long-term-services-supports/katie-beckett-waiver.html

Tennessee created a program in 2020 for children under age 18. These are children who:

- Have disabilities or complex medical needs, and
- Do not qualify for Medicaid because of their parents' income or assets (like bank accounts or other property).

The program has two parts or groups:

Part A is to serve children with the most significant disabilities or complex medical needs. These are children who would qualify for care in an institution but whose families want to care for them at home instead. Their parents' income and assets would not be counted in determining their eligibility for Medicaid. If they qualify, they would receive full Medicaid benefits to help pay for care their private insurance doesn't cover. They may also receive Home and Community Based Services (HCBS) for other things they need that Medicaid and private insurance do not cover. Parents may be required to purchase private insurance and pay premiums for Medicaid (on a sliding fee scale based on income) to help offset program costs.

Part B is also to serve children with disabilities or complex medical needs. However, Part B is for children who don't qualify to receive care in a medical institution but are "at risk" of needing institutional care unless they can get care at home. Children in Part B would not be enrolled in Medicaid. They would receive up to \$10,000 per year in services to help them cover the cost of private insurance premiums and things their insurance does not cover. The Department of Intellectual and Developmental Disabilities (DIDD) runs Part B.

4. Autism Insurance Coverage (Tennessee became the last state to mandate coverage)

autismspeaks.org/tennessee-state-regulated-insurance-coverage

The Tennessee Department of Commerce and Insurance now requires all individual, small and large group insurance plans issued in the state to cover treatment for autism that is “medically necessary and appropriate and is not experimental,” including applied behavior analysis (ABA) at the same level as any other medical condition.

5. Supplemental Security Income for Disabled Children (Social Security Administration, 2020)

ssa.gov/pubs/EN-05-10026.pdf

Children with certain defined medical conditions may be eligible for Supplemental Security Income. Conditions include:

- Total blindness
- Total deafness
- Cerebral palsy
- Down syndrome
- Muscular dystrophy
- Severe intellectual disability (child age 4 or older)
- Symptomatic HIV infection

Eligibility may need to be determined by a medical examination or test provided at no charge to the caregiver by the Social Security Administration’s Disability Determination Services office.

6. Family Support Program (Tennessee Department of Intellectual and Developmental Disabilities, Adult Services, 1992)

tn.gov/didd/for-consumers/family-support.html

This reimbursement program is funded by Tennessee state dollars and designed to assist individuals with severe disabilities and their families to remain together in their homes and communities. Family Support is not a substitute for more comprehensive services provided under other programs, including the Medicaid HCBS Waiver, TennCare, Medicare, or private insurance.

↘ Section 3: Advocacy

Family advocacy provides better outcomes than medical and social services advocacy alone. Each family has an intimate knowledge of their own situation that cannot be obtained from an outside source.

- 1.** You are the expert of your own experience, so there is value in your personal story. The personal is the political. As you navigate systems and policies to meet the needs of your family, consider the personal impact that this system / process / policy issue has on your family and capture that and create your story.
- 2.** Your legislators are fellow Tennesseans and are as approachable as your child's teacher, a neighbor, or a co-worker. They are individuals much like yourself who need guidance from constituents about how policy is shaped to best meet the needs of those whom they represent. Creating that relationship is important. Remember you have intimate knowledge of your needs and those of your child that is valuable to legislators.
- 3.** Try to find a legislative source or advocacy group that shares similar interests. These sources are great references to alert you of potential legislation that might warrant a conversation with your elected representatives.
- 4.** Call your representatives. For some bills, as few as three calls can indicate major interest from constituents. Be prepared to leave your statement with name and ZIP Code so your legislator knows that you live in their district.
- 5.** Always leave your legislators with a specific request. It can be as simple as asking them to vote "yes" or "no" on a piece of legislation that you have educated them about.
- 6.** VOTE! Elected officials look to see if you have a voting record. That record shows if you have any power in keeping them in their elected position. Whom you vote for is not on public record, however legislators can see if you have voted in the past.



Groups to Help with Advocacy

You don't have to do this alone. There are organizations and advocacy groups that are there to help you learn how to best advocate for your needs and the needs of your family.

The Arc Tennessee

thearc.org/policy-advocacy

Disability Rights Tennessee

disabilityrightstn.org

Family Voices of Tennessee

tndisability.org/familyvoices

Tennessee Disability Coalition

tndisability.org

Vanderbilt Kennedy Center. (2020, January 16). *Educate to Advocate* [Video File] Retrieved from vkc.vumc.org/events/6366

Mclaughlin, A., Glang, V., Beaver, M., Gau, M., & Keen, M. (2013). Web-Based Training in Family Advocacy. *Journal of Head Trauma Rehabilitation, 28*(5), 341–348. doi.org/10.1097/HTR.0b013e31824e1d43

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➤ Section 4: Political Process in Tennessee

Political Process in Tennessee

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Step-by-Step

1. A problem exists within society and a draft of a bill is written that seeks to alleviate the harm being done. This bill may be prompted by a legislator or by outside interests like citizens, businesses, or special interests who contact a legislator.
2. Stakeholders including constituents, businesses, and special interests may seek to change a bill at any time within the process although most often this occurs at the beginning of the drafting process. This is done by contacting the legislator introducing the bill or one's own representative who can also introduce an amendment once it reaches the floor of the House or Senate.
3. A bill is delivered by a representative or senator to the Chief Clerk of the House or Senate who makes sure it is formatted correctly.
4. When a bill is ready to be introduced to the legislature, it is done so by a sponsor. A sponsor is a representative in either the House or Senate. There can be multiple sponsors for the same bill, this is called co-sponsoring and may be more successful as it shows more representatives on board with the bill initially.
5. After being introduced, the bill is then referred to committee (or sub-committee). You can find a list of Tennessee House and Senate committees here: www.capitol.tn.gov/committees/. Committees are subject to change and others may be added or deleted as legislators see fit.
6. Upon referral to a specific committee, a bill is placed on the committee's "calendar," essentially an agenda of bills and other business.
7. When it reaches the top of the calendar, a committee will debate and revise the bill making amendments as the committee members see fit. A vote is taken on each amendment and then on the final bill. Lawmakers who oppose a bill may move to "table" it, which essentially kills the bill by taking it off the agenda. If a bill is not tabled, it can be sent to a subcommittee or back to the chamber (House or Senate) in which it was introduced.

If a bill is sent to a subcommittee, the process that occurred in committee largely repeats. If a bill is approved out of subcommittee, it is then referred back to the committee. Bills progress through these steps simultaneously and independently, but all must be reconciled by both House and Senate chambers before a vote is called.

8. If the bill makes it back to the chamber from committee, it is then put on the chamber's calendar.
9. When it reaches the top of the calendar, it is then debated by the chamber. Amendments may be introduced and voted upon. When this is done, the final bill is voted on. Note that the legislators may ask a bill be tabled for a period of time or indefinitely. If a majority votes to pass the bill, it is then transferred to the other chamber where the introduction, committee, and voting process begins again.
10. If passed by the other chamber with no amendments, the bill is then brought to the governor's desk. If passed with amendments, it is sent back to the other chamber so a vote can be taken on the amended bill.
11. The governor can sign the bill into law or veto the bill. If the bill is vetoed, it goes back to the House and Senate where a simple majority vote can override the veto making the bill a law. A governor has 10 days upon receiving a bill to decide to sign or veto it.

FAQ's

Who is my legislator?

You can find your legislators by following this link and submitting your street address and ZIP Code. wapp.capitol.tn.gov/Apps/fmlv3/districts.aspx

Where can I track a bill?

You can track bills in Tennessee using the following link: capitol.tn.gov/legislation/

How can I contact my legislator or another chamber official?

Use the following directory link: capitol.tn.gov/directory/

When is the legislature in session?

Session begins the second Tuesday in January at 12:00 p.m. There is no defined adjournment date, but the General Assembly usually adjourns in mid-April.

Where can I find the current Tennessee Code of Laws?

Use the following link: advance.lexis.com/container?config=014CJAA5ZGVhZjA3NS02MmMzLTRIZWQtOGJjNC00YzQ1MmZINzc2YWYKAFBvZENhdGFsb2e9zYpNUjTRaIWVfyrur9ud&crd=fcc2540f-20ff-4a05-8984-30d7aaa62eb9&prid=4b357a28-7e73-4edf-8316-577c8d085359

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