

## **ABLE Act and Special Needs Trusts**

A review of the available financial planning tools  
to promote independence for people with disabilities

Summary of purpose: This report is a primer to discuss the **ABLE Act** and **Trust** options for people with disabilities and parents of children with disabilities to help them better understand (and choose) the best mix of financial life-planning options for their family. The intention is to provide an overview of how **both life-planning tools** can be best used to support financial independence for people with disabilities. The report is not intended as an in-depth look at each subject; however, there are additional resources included for those who wish to learn more.

This report is divided into multiple stand-alone sections for quick reference. The sections are as follows:

Sections	Page:
• Introduction	1
○ Medicaid Asset Cap	3
• ABLE ACT	4
○ Texas ABLE Act	11
• Special Needs Trusts	16
• Comparisons and Contrasts	21
• ABLE and Trust - Working in Unison	22
• General recommendations	22
• Policy recommendations	24
• Acknowledgements	25

### **Disclaimer**

The information provided in this report on the ABLE Act, Texas ABLE Act, and Trusts is a compilation and distillation paraphrased from a variety of books, online resources, estate planning and elder law lectures, research, personal communications, and personal experience. It is “Texspecific,” while it references federal programs and other states' ABLE programs, the focus and point of view is as Texans, for Texans. No staff member at the Coalition of Texans with Disabilities or any of the project’s funders is an estate or financial planner. We are advocates involved and concerned with removing barriers for people with disabilities to full participation in the community of their choice. In addition, every estate planner, lawyer, or trustee may offer only certain services and limit the general options of a particular trust program to better suit their business model. Not every aspect of each individual financial planning tool will be available in every circumstance.

Furthermore, this document provides a snapshot of the laws, regulations, and activities before July 31<sup>st</sup> of 2016. The ABLE Act has already seen many changes since it became law,

and there is an expectation that there will be more as the details are solidified and programs become available and evolve.

Last and not least, Federal and State rules and guidance have been written and issued at a dizzying pace for a new and innovative program like the ABLE Act, with the expectation that additional future amendments will change the ABLE program even more and have a widespread effect on special needs trust laws, guardianship laws, transition planning, and Social Security rules and regulations.

It is absolutely essential that anyone (individuals, parents, loved ones, advocates, and planners) involved in crucial life-planning decisions is informed and involved when making decisions that have such a massive impact on a person with a disability's future.

### **How we got here**

People with disabilities cannot live without some type of healthcare coverage. And, in many cases, the only viable option is to apply for and meet the requirements for healthcare coverage through the [State of Texas Medicaid](#) program. In order to be (and remain) eligible for Medicaid coverage, an individual's "countable resources" must be less than \$2,000, including cash, savings, stocks and bonds, life insurance (with a cash value), any vehicles, or any property other than a primary residence. Although there are some exceptions (such as a primary vehicle if used for "medical purposes") many things a person would need to maintain a full life are not considered an exclusion.

The asset cap of \$2,000 (for an individual) is simply not enough money for a person living in the community to pay for minor emergency expenses – much less major expenses such as car repairs. There is simply little or no personal financial safety net with this relatively small amount of savings in today's world. In addition, the penalties that can be leveraged for having funds over the limit can result in a person losing Medicaid eligibility for a month or more (depending on the amount).

It is difficult at best for people with disabilities to grow wealth or create financial stability with barriers in place like the Medicaid asset cap (also called a Resource Limit). Even with existing programs, such as [Medicaid buy-in](#), which allows a person to pay for their own Medicaid coverage on a sliding payment scale, it has become increasingly difficult for a person with a disability to work and build enough personal savings to participate in alternative programs. For many people, attaining meaningful and competitive work is simply not worth the risk of losing crucial services and supports.

Furthermore, restricted incomes and lack of savings or assets severely restricts the borrowing power of many people with disabilities who have no other avenue than using expensive non-bank alternatives, such as pawn shops or title loans, to access the funds needed to make repairs on a vehicle, pay for supplemental health care, or pay for emergency durable medical equipment that cannot wait for a lengthy approval process from a health plan or state agency.

The unreasonable and restrictive Medicaid asset cap has created a system of “forced poverty” that has not changed in a dynamic and growing economy in decades and has left people with disabilities out of experiencing and fully participating in the American dream.

The following chart illustrates the asset limit for 2015 – 2016 in Texas and includes the income cap as well as the amount of assets that a married couple is allowed to maintain.

**Texas Medicaid Income Limits & Asset Limits (2015 - 2016)**

Income Cap (individual)	\$2,199 per month
Income Cap (married both are on Medicaid)	\$4,398 per month
Countable Asset Cap (individual)	\$2,000
Countable Asset Cap (married both are on Medicaid)	\$3,000

The last time the **asset limit was adjusted** by Federal law was an attempt in the late 80’s to address the situation (Figure 1.). In **1986** the cap increased \$300 increase and eventually added another \$200 by **1989** to reach the current \$2,000 cap. **That was 27 years ago!** The last time *both the general and earned income disregard was adjusted* was 1972! Forty-four years ago you could buy a loaf of bread for 25 cents and a gallon of gas for 52 cents. The **cost of living has increased over 5.5 times** while the disregards have stayed the same.

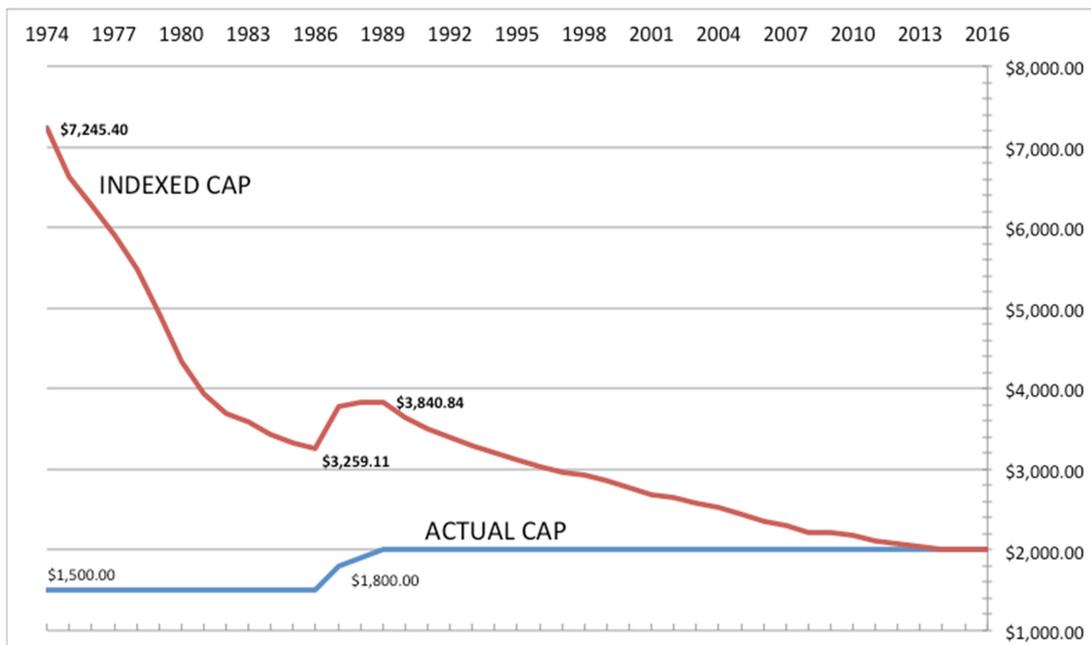


Figure1. The [CPI inflation calculator](#) uses the average Consumer Price Index for a given calendar year. This data represents changes in prices of all goods and services purchased for consumption by urban households. This index value has been calculated every year since 1913. For the current year, the latest monthly index value is used.

## **Help on the Way**

The current Asset cap system is woefully out of step with the economic realities faced by people with disabilities who currently live in an increasingly expensive world with rising medical costs and less coverage by governmental services and supports.

However, with the widespread use of Trusts, and the recent passage of the ABLE Act, financial vehicles do exist in sufficient variety and in ease-of-use to address the restrictions imposed on people with disabilities by the Medicaid asset cap. Trusts can be used to place assets in an account that gives another party (a trustee) the right to hold and manage assets for the benefit of a third party in order for the beneficiary of the trust to retain crucial services and supports. An ABLE Account is a hybrid checking/savings account that may be self-managed that also is exempt from the Medicaid asset cap.

Both an ABLE Account and Trusts and have vast potential to provide much needed supplemental funds for persons with disabilities and should be considered as complimentary financial tools with a single mission. With careful trust tailoring and choosing the best ABLE plan to suit the individual's or family's needs, both tools can be valuable to assist a person with a disability to achieve financial security and to promote independence and community living.

---

## **Achieving a Better Life Experience Act (ABLE Act):**

On December 19, 2014, one of the most significant pieces of legislation for people with disabilities in more than twenty years was signed into law. The Stephen Beck, Jr. *Achieving a Better Life Experience Act* (ABLE Act) allows a qualified person with a disability to save money (in their own name) in a tax-advantaged account that is exempt from the \$2,000 Medicaid asset cap.

ABLE accounts can greatly improve the lives of people with disabilities and remove many of the systemic disincentives that have enforced poverty-like conditions on those who require assistance and support programs for crucial needs such as health care and housing.

For the first time in U.S. history, a person with a disability can use a self-directed ABLE Account to earn income, save money, build wealth, and pay for a wide variety of expenses without fear of losing their services and supports. In addition, ABLE Accounts can be flexible, are far simpler to set up and manage, and should be very cost-effective in comparison to other financial planning and savings vehicles for people with disabilities. These accounts can be self-directed, supported, or managed by a professional. Therefore, ABLE Accounts could (and should be) an essential tool for independence and community living for all people who qualify.

## **ABLE to the Rescue**

The ABLE Act began as a proposed federal law ([H.R. 647](#)) that was amended to the [Tax Extenders Package bill](#) passed in December of 2014 and further amended via [H.R. 2029](#) (the Consolidated Appropriations Act of 2016) the following year.

The summary of the legislation leaves no interpretation to what the legislative intent (the purpose) was when writing the ABLE act:

*Qualified ABLE Programs - (Sec. 101) States as the purposes of this title to: (1) encourage and assist individuals and families in saving private funds for the purpose of supporting individuals with disabilities to maintain health, independence, and quality of life; and (2) provide secure funding for disability-related expenses of beneficiaries with disabilities that will supplement, but not supplant, benefits provided through private insurance, title XVI (Supplemental Security Income) and title XIX (Medicaid) of the Social Security Act, the beneficiary's employment, and other sources.*

*(Sec. 102) Amends the Internal Revenue Code to exempt from taxation a qualified ABLE program established and maintained by a state, or by an agency or instrumentality of the state, to pay the qualified disability expenses related to the blindness or disability of a program beneficiary, including expenses for education, housing, transportation, employment training and support, assistive technology and personal support services, health, prevention and wellness, financial management and administrative services, legal fees, and expenses for oversight and monitoring, funeral and burial expenses.*

For over eight years, advocates worked diligently with a variety of Federal legislators to craft the eventual bill. Parents of children with disabilities were deeply involved in the process and were extremely vocal in asking for legislative support in conjunction with national disability organization's coordinated outreach efforts.

The lawmakers heard the advocates and voted accordingly. In the U.S. House of representatives there were 380 cosponsors (194 Republicans and 186 Democrats). Thirty-four of those were from Texas (22 Republicans and 12 Democrats). In the Senate there were 78 cosponsors (47 Republicans, 29 Democrats, and 2 Independents) none of which were from Texas. The ABLE Act was truly a bipartisan effort.

After passage of the Federal enabling legislation, individual states had to craft and pass similar ABLE implementation laws. Some states moved quickly with impending legislative sessions, while other took a more measured approach. As of July 31, 2016, 47 states (including Texas) have passed a version of implementation legislation, while one more state is pending. Only two states who have introduced legislation have been unsuccessful. Historically, the pace at which ABLE implementation laws were passed is unprecedented. Disability groups have called this, "a national movement."

As of July 31, 2016 four states have created and launched ABLE programs. Each program is different and fits a variety of needs for people with disabilities. And, due to the elimination of an in-state residency requirement in an amendment in 2015 to the original law, anyone can participate in any ABLE program in any state that offers an out-of-state option.

### **For More Information:**

Articles from National groups on this landmark legislation:

- [ABLE Act Becomes the Law of the Land](#) – National Down Syndrome Association
- [ABLE Act](#) – Representative Anders Crenshaw – Florida
- [Obama Signs ABLE Act](#) - Michelle Diament - Disability Scoop

Texas focused articles

- [A game-changer for Texans with disabilities](#) – TribTalk - Erin Lawler
- [New ABLE savings accounts will help disabled Texans](#) – Star-Telegram – Teresa McUsic

### **What is an ABLE Account?**

An **ABLE** Account is a hybrid savings or checking account with limitations on how much you can save, how you can invest, and what you can spend your savings on. The concept was based on a [529b \(education plan\)](#) which is designed as a college (and other post-secondary) savings plan. An ABLE Account's primary function is to supplement, not supplant (replace, governmental assistance programs).

There is no residency requirement as the Federal act was amended in 2015 to allow a person to have an account **in any state** that has an enabled program. However, a beneficiary can have only one ABLE Account.

An ABLE Account may be 100% self-directed. However, some people with disabilities may need help managing the account. Furthermore, parents or supporters may need to limit the ability to withdrawal funds in some manner. For example, it might not be in the best interest of a person with an ABLE Account who just turned 18 to have unlimited access to a \$100,000 account with a debit card!

An ABLE Account has specific qualified expenses for which the funds in the account can be used. Using funds for non-qualified expenses may incur taxes and penalties. An account beneficiary (or a supporter) is responsible for ensuring that the funds are spent properly, and they **absolutely must keep detailed records of expenses and justifications for every purchase**. The tax forms for an ABLE Account are relatively simple, but must be submitted each year.

ABLE Accounts are very flexible and have the potential to help a great many people with disabilities in their daily lives. However, with this new tool there is also a responsibility to adhere to the restrictions, reporting, and procedures of the plan.

## How the Program Works

Each year, an account beneficiary (*the person who receives the benefit of the account*) can save a total aggregate (*combined*) amount of \$14,000 into an individual ABLÉ Account. The funds can come from earned wages, a family member, a friend, or any other source. Each account can have as much as \$100,000 (and have \$2,000 in other cash assets) before the beneficiary's Supplemental Security Income (SSI) monthly payments are suspended (SSDI income is exempt). The beneficiary will always retain their Medicaid coverage. A beneficiary's account can have more than \$100,000 in it as each state's law for 529 accounts varies. Texas law allows for a maximum amount of \$370,000.

For example, a person with an **ABLE** Account might earn \$6,000 throughout the year beyond their personal expenses. They could save that money in their **ABLE** account. In addition, a grandparent might wish to put another \$6,000 into the account, and the beneficiary's parents might add another \$2,000 to reach the \$14,000 maximum deposit limit. No more money could be deposited into that account that year. The following year the maximum of \$14,000 can again be deposited. Assuming very small returns on investments and no withdrawals, the account would be at or near \$100,000 in approximately seven years. At \$100,000 any SSI payments that the beneficiary received would be suspended but the beneficiary could continue to deposit money in the account until the account reached \$370,000 (approximately 26 years).

These funds could be used at any time (depending on the ABLÉ program's guidelines for expenses) for a variety of disability related expenses (see below) to ensure financial stability and that the account owner can live a self-directed and independent life.

## Characteristics of ABLÉ

### Who Qualifies

Any individual who has a significant disability that was diagnosed before the age of 26, regardless of their current age, qualifies for an account.

Those who meet the age criteria, and are already receiving financial (income) disability supports via Supplemental Security Income (SSI) or Social Security Disability (SSDI) benefits (Title XVI or Title II of the Social Security Act) automatically qualifies.

Age 26 and receives SSI or SSDI = automatic approval

**Or**, a person must submit a "disability certification" assuring the program manager that the individual beneficiary has and will retain documentation of a physician's diagnosis and signature, which confirms that the individual meets the functional disability criteria in the ABLÉ Act (related to the severity of disability described in Title XVI or Title II of the Social Security Act).

No other disability-related program allows for the “self-certification” of disability. Therefore, individuals, parents, or supporters must take great care in gathering and keeping all documents that are required by the specific ABLÉ plan in which they participate. It is crucial to have these documents on hand in case of an audit. Disability certification is discussed in more detail in the “Deep in the Weeds” section.

### **What expenses qualify?**

While the IRS has not established the exact details at this time, the funds in an ABLÉ account may be used on qualified disability expenses in the following categories:

- Education
- Housing (there may be exceptions)
- Transportation
- Employment training
- Assistive technology
- Personal support services
- Health prevention and wellness
- Financial management
- Administrative services
- Legal fees
- Funeral and burial services
- Other expenses

These categories are extremely broad and incorporate aspects of daily life that have never been available in other savings vehicles (such as special needs trusts). However, as broad as they are, there are expectations that the approvals for certain specific items within the broader categories may require review and approval by either the U.S. Treasury and/or the Social Security Administration. Beneficiaries who are using an ABLÉ Account may have to endure a period of uncertainty with qualified expenses. However, it is expected that no one will be penalized as these issues work themselves out. The early adopters of ABLÉ Accounts may see more flexibility of qualified expenses, which may cease to be case as time goes by.

### **Medicaid Estate Recovery Program (MERP)**

The ABLÉ program is essentially a community living tool. As such, it is unclear at this time how much (or what percentage) of the funds remaining in an account after a beneficiary dies may be (or not be) subject to the [Medicaid Estate Recovery Program \(MERP\)](#). The MERP is a payback provision that reimburses the State that a beneficiary lives in for Medicaid expenses that were incurred during a beneficiary’s lifetime. By federal law, ABLÉ Accounts are 100% subject to MERP. The Department of Aging and Disability Services (DADS) is responsible for managing the MERP in Texas. However at the time of publication, no specific rules incorporating or excluding ABLÉ from MERP have been proposed or enacted.

**For More information:**

- [ABLE Accounts: 10 Things You Should Know](#) – ABLE Resource Center
- [New ABLE Accounts for the Disabled Help Parents Save For Future Care](#) – Forbes - Richard Eisenberg

**Deep in the Weeds**

From imagining the concept of a savings program that would be exempt from the Medicaid asset cap to launching the final Texas ABLE program, there has been a complicated series of interactions between Federal agencies, state agencies, state board, program managers, and consumers. Figure 2 provides a graphic flow chart of the agencies laws, oversight, and guidances that interact for a Texas ABLE to exist.



Figure 2.

As many moving parts as it has, in comparison to many governmental program launches, the ABLE program has moved with lightning-speed.

The following timeline provides a frame of reference for when the various bills, laws, and guidances were passed, published, or released. Of note, Texas passed SB 1664 prior to the proposed Federal guidelines being released, as did many states. Links have been added to the documents for those who are interested in specific details.

- Dec. 19, 2014 - Federal [ABLE Act](#) passes and signed into law
- March 10, 2015 - The U.S. Treasury and the IRS [Interim Guidance](#)
- May 30, 2015 - Texas unanimously passes [Texas ABLE Act](#)
- June 19, 2015 - The U.S. Treasury and the IRS [published proposed guidelines](#)
- Sept. 19, 2015 - 90 days [comment or suggestion](#) period for the proposed guidance rules
- Oct. 14, 2015 - Public hearing in Washington DC for verbal comments on the proposed rules
- Nov. 20, 2015 - The U.S. Treasury and the IRS [Additional Guidance](#)
- Dec. 01, 2015 - Texas Comptroller appoints the "ABLE program advisory committee" members
- Dec. 17, 2015 - [Federal Law amended](#) - Removed Residency Requirement
- May. 12, 2016 - Department of Disability and Aging Services approves [ABLE exemptions rules](#) for Medicaid
- July 8, 2016 - The Prepaid Higher Education Tuition Board [publishes rules for 30-day comment](#)
- Aug. 6, 2016 - Last Day for Texas ABLE rules comments

### **Self-Certification**

While many of the guidances have been very important to the design of the final ABLE programs, one key issue, **self-certification**, is perhaps the most important to people with disabilities. As stated in the "ABLE" section, no other disability-related program allows for the "self-certification" of disability.

### **But, what does self-certification actually mean?**

The Treasury and Social Security Administration (SSA) has provided recommendations and guidelines such as:

- *"Those who meet the age criteria, and are already receiving financial (income) disability supports via Supplemental Security Income (SSI) or Social Security Disability (SSDI) benefits (Title XVI or Title II of the Social Security Act) **automatically qualifies**", and*
- *"a person must submit a "disability certification" assuring the program manager that the individual beneficiary has and will retain documentation of a physician's diagnosis and signature, which confirms that the individual meets the functional disability*

*criteria in the ABLE Act (related to the severity of disability described in Title XVI or Title II of the Social Security Act)."*

Regardless of the vagueness of the Federal law, it is important to follow the guidelines that each program sets for self-certification and to take great care in **gathering and keeping** all required documents in case of an audit by the Social Security Administration or the U.S. Treasury.

As an example, the [Ohio STABLE Account](#) has a [detailed eligibility section](#) on their website with guidelines and an "eligibility quiz" that will walk a perspective participant through a series of questions to help the individual decide if they meet self-certification eligibility standards. This particular program includes a **written, signed diagnosis from a licensed physician, and** that the individual is either:

- (1) blind, within the meaning of the Social Security Act, or
- (2) has a medically determinable physical or mental impairment that results in "marked and severe functional limitations"

Of note, in contrast to Federal Social Security requirement, there is no "substantial gainful activity" (SGA) requirement which the Social Security Administration uses to determine qualifications for SSI payments for adults. As an aside, in 2016, SGA is defined as earning \$1,130 or more a month from working, or \$1,820 for blind people. If a person earns more than those amounts, they cannot receive SSI income. However, that person with a disability could qualify for an ABLE Account if they need to retain Medicaid coverage or were using Medicaid Buy-in.

As stated above, it is absolutely crucial to be very detailed in the documentation and reporting of qualified expenses. It is just as important to be careful and responsible with self-certification. A beneficiary must make every effort to procure and maintain the appropriate documentation for a self-certification of disability. This concept opens ABLE to those who may not receive SSI payments, for those who may have difficult-to-diagnose disabilities, and for those with behavioral or mental health disabilities. It is imperative that the disability community treat self-certification seriously and with the respect that has been granted to them by the authors of the ABLE act.

## **Texas ABLE Act**

As important as the Federal ABLE Act is, individual States were tasked with enabling a similar law in each state and creating an ABLE program. Texas quickly moved to pass the **Texas ABLE Act** ([Senate Bill 1664 – Sen. C. Perry](#)) by May 30, 2015. SB1664 was a consensus bill with many disability groups involved in drafting and supporting the legislation (see list in acknowledgments). The Texas ABLE Act mirrors the Federal legislation in intent and places a very high value on consumer involvement. **It has been estimated that over a half-million Texans could benefit from having an ABLE Account!**

As with the Federal ABLE Act, the Texas ABLE Act was a true bipartisan bill, supported by both political parties. SB 1664 had five coauthors (2 Republicans and 3 Democrats) while the House of Representatives companion bill ([HB 3766](#)) had nine coauthors (6 Republicans and 3 Democrats). At no time during the entire process of navigating the Texas legislature did the bills receive any negative votes. It is a tribute to the hard work and dedication of each author’s staff that this bill was clearly understood to be of great value to people with disabilities.

**Texas Senators and Representatives who supported TX ABLE in the 84<sup>th</sup> Legislature**

<u>Senate</u>	<u>House of Representatives</u>
Primary Author - Senator Charles Perry	Primary Author – Rep. Cindy Burkett
Coauthors	Joint Authors
Sylvia Garcia	Larry Gonzales
Jose Rodríguez	Eddie Lucio III
Charles Schwertner	Ron Simmons
Kirk Watson	Andrew Murr
	Coauthors
	Elliot Naishtat
	Gilbert Peña
	Sylvester Turner
	John Zerwas

**Who’s in charge of Texas’ program?**

The [Texas Prepaid Higher Education Tuition Board](#) (TPHETB) was tasked with administering the Texas ABLE program, including development and implementation of the program, creation and adoption of rules, and establishment of policies and procedures. TPHETB currently administers and provides oversight for all of the Texas college savings programs, including the Texas Guaranteed Tuition Plan, Texas College Savings Plan, LoneStar 529 Plan, and Texas Tuition Promise Fund. TPHETB is chaired by the [Texas Comptroller of Public Accounts](#) (CPA) and supported by the Comptroller’s staff. Many states chose to place the ABLE programs with state treasurers due to the similarities of the ABLE program and the 529b college savings programs that typically fall under the purview of state treasurers.

It is expected that other Texas state agencies that provide services and supports for people with disabilities will interact with the Texas ABLE program. The Texas Education Agency will likely incorporate outreach information for youth in public schools when providing transition guidance and services. In addition, the Texas Workforce Commission will need to include ABLE Account information for the newly transferred Vocational Rehabilitation programs (formerly house at the Department of Assistive and Rehabilitative Services) as part of its employment services.

Only the Department of Aging and Disability Services (DADS) has been actively involved with the Texas ABLE program (other than the Texas CPA) at this time. DADS has [passed rules that exclude the funds in ABLE Accounts](#) “used to establish, are held in, interest earned, and payments for expenses from income and resource calculations in determining financial eligibility” for:

1. Ch. 358 - Medicaid Eligibility for Elderly and People with Disabilities (MEPD) program.
2. Ch. 359 - Qualified Medicare Beneficiary (QMB) program, and Qualified Disabled and Working Individual (QDWI) program.
3. Ch. 360 - Adult Medicaid Buy-in (MBI) program.
4. Ch. 361 - Medicaid Buy-in for Children (MBIC) program.

DADS is also responsible for managing the Medicaid Estate Recovery Program (MERP) (see “ABLE characteristics - p.8” and throughout the “Trust” section). However at the time of publication, no specific rules incorporating or excluding ABLE from MERP had been proposed or enacted.

### **What’s next and when?**

As of July 31, 2016, the Texas Prepaid Higher Education Tuition Board (TPHETB) has drafted rules to govern the program and the [proposed rules have been published for 30-day public comment](#). The deadline for public comment will be August 6<sup>th</sup>, and the rules (and comments) will be submitted to TPHETB for consideration to adopt at their Aug. 16th meeting, along with any comments received.

There is no date set for Texas’ program to begin. However, the Texas Comptroller has created a website to educate Texans and to share information about the forthcoming program ([www.texasable.org](http://www.texasable.org)).

### **Nothing about us without us**

One of the unique features of the Texas ABLE Act that does not exist on some of the other state’s programs is the inclusion of an advisory committee to the help the [Texas Prepaid Higher Education Tuition Board](#) (TPHETB ) understand the unique needs of the people who will be using Texas ABLE Accounts. The advisory committee consists of consumers with disabilities, parents, and allies in the disability community. In fact most of the seven members meet more than one of the criteria for being appointed to the advisory committee, which are:

- a. person who qualifies for an account,
- b. family member of a person with a disability,
- c. representative from a disability organization,
- d. financial community representative.

This committee has been very active in providing guidance during the rule making process and outreach at disability events.

## **Is an ABLE Account for me?**

Not everyone needs an ABLE Account. Other useful estate planning tools exist that may better suit your personal needs. As regulations become clearer and implementation gets underway, families and estate planners will be better able to weigh which savings method would be best for each individual.

## **Where and when can I get an ABLE Account?**

At the time of publication, only four states have implemented a fully functional ABLE program. Ohio's [STABLE](#) Program, Tennessee's [ABLE TN](#), Nebraska's [ENABLE Savings Plan](#), and Florida's [ABLE United](#) (not accepting out-of-state-residences) all allow for application to, deposits to, investments in, and distributions from a qualified ABLE Account.

To help understand the differences between available programs, the [ABLE Resource Center](#) tracks all of the ABLE programs and recent developments with the ABLE Act. In addition, the National Down Syndrome Society has published a [useful chart](#) to that allows for a quick view comparison of available programs. Both resources can help consumers choose the most appropriate program for their or their family's needs, as each program is substantially different in how they apply the concepts of the ABLE Act.

Once again, there is no date set for Texas' program to begin. However, the Texas Comptroller has created a website to educate Texans and to share information about the forthcoming program ([www.texasable.org](http://www.texasable.org)).

Several states are in discussions to create on a consortium that will share expenses and resources in order to serve more beneficiaries. At the time of publication, there is no date set for this program to begin. Other states have various dates targeted for their plans to be available.

The authors of this report felt that to provide a comparison and contrast for the three newly created programs would not be useful as these are new programs and may change significantly as other programs become available. However, this report does compare and contrast the concepts between an ABLE account and a special needs trust beginning on page 16.

## **ABLE may change again**

Pending Federal legislation may change the ABLE act yet again. The following bills (and companion bills) seek to address three of the shortcomings of the current law. While it is uncertain how long it will take to for these proposed bills to go through the process to become laws, it is clear that each one could have a significant and far-reaching impact on the disability community.

The three bills have been grouped together by national disability groups in an outreach package called the “ABLE Act Improvement Bills.” They have each gained a significant number of supporters in another bipartisan effort of both the U.S. House of Representatives and Senate. And, the authors are (once again) disability rights supporters (some who have children with disabilities), including Texas Representative Pete Sessions.

1. The ABLE to Work Act ([HR 4795](#) / [S 2702](#)) will enable ABLE beneficiaries who work and earn income to save additional amounts in their ABLE account above the current annual maximum contribution (currently \$14,000). Specifically, an ABLE beneficiary who earns income from a job could save up to the Federal Poverty Level (currently \$11,770) in addition to the \$14,000 annual maximum contribution for a total maximum annual saving potential of \$25,770. In addition, a beneficiary may be eligible for the “Saver’s Credit” an existing federal tax credit that low and middle-income individuals can currently claim when they make contributions to a retirement account. [HR 4795: 28 cosponsors: 19 Rs & 9 Ds – 2 from Texas] [S2702: 5 cosponsors: 3 Ds & 2 Rs]

2. The ABLE Financial Planning Act ([HR 4794](#) / [S 2703](#)) will enable ABLE beneficiaries to rollover typical 529 (education) accounts to a 529A (ABLE) accounts and will also allow for a reverse-rollover if the beneficiary ceases to be disabled. This bill is particularly helpful for families who set up 529 accounts before receiving a child’s diagnosis, or for teenagers who incur life-changing events that render them unable to go to college and use their 529 funds for their original purpose. [HR 4794: 11 cosponsors: 8 Rs & 3 Ds – 1 from Texas] [S2703: 2 cosponsors: 1 D & 1 R]

3. The ABLE Age Adjustment Act ([HR 4813](#) / [S 2704](#)) will raise the age of onset of disability from 26 to 46. This will enable more individuals who become disabled later in life to take advantage of the benefits of ABLE accounts. [HR 4813: 13 cosponsors: 9 Rs & 4 Ds – 1 from Texas] [S2704 2 cosponsors: 1 D & 1 R]

**For More Information:**

- [Congress May Consider Tweaks To ABLE Accounts](#) – Disability Scoop - Michelle Diamant
- [ABLE Act Improvements Factsheet](#) – The Arc
- [Congressman Van Hollen Announces Bipartisan, Bicameral Legislation to Expand ABLE Accounts](#)

## Trusts

### Introduction

Trusts are estate/life-planning tools that have been used to supplement long-term services and supports for people with disabilities while maintaining a variety of governmental services and supports. Until the passage of the ABLE Act, trusts were the only financial vehicle to fill this function. Trusts are extremely useful tools (especially for the elderly who are divesting or wish to prepare for assisted or nursing home living). However, they are designed **not to be self-determined** and a trust may be expensive to create and manage. Trusts are used in many cases when the beneficiary is not considered competent to manage their own finances due to a cognitive disability, severe physical disability, or aging.

This section has been specifically written for parents and loved ones of children with disabilities, as these groups often have the most questions and have received misinformation about how trusts work and are managed. Other groups may also find the information useful. It is important to note that a trust is only one aspect of life/estate planning and is typically used in conjunction with a power of attorney, wills, HIPPA authorization, guardianship, and a variety of other legal tools.

---

### *Parents, why do we need to learn one more thing?*

*Because we have to...* in order to make sure we don't jeopardize the necessary services and supports that can help our children retain their independence.

Services, Assistance, and Supports such as:

- Medicaid
- Community Living Waivers
- Supplemental Security Income (SSI)
- Housing assistance

It's simple: If we (or anyone else) gives, wills, or donates money to our children in almost any way, they may become ineligible for services.

### **What are some of the ways we protect our children's services and supports?**

By utilizing sometimes-complex financial instruments called **trusts**. There are 37 types of trusts that are used to protect assets from creditors, misuse of funds, the government, and for other uses including living trusts, irrevocable trusts, blind trusts, and special needs trusts.

## Basic Trust Terminology:

1. **Trustee:** The person designated in the Trust Agreement to take possession of the trust assets and manage those assets. The Trustee must also preserve and manage the assets according to the provisions in the Trust agreement.
2. **Trust Agreement:** The Trust Agreement is the document that creates the Trust and sets out the provisions related to the Trust. For instance, it will generally designate the trustee, the beneficiaries, and the purposes of the Trust. It will also typically include provisions designed to guide the trustee in fulfilling his duties.
3. **Grantor:** The person(s) who creates the Trust Agreement. In order for the Grantor to create a valid trust, (s)he must designate a trustee and a beneficiary. (S)he must also transfer assets into the Trust.
4. **Beneficiary:** The Trust Beneficiary is the person(s) who receives the benefit of the assets in the Trust.

## Special Needs Trusts

As parents of children with disabilities, the most useful trust option is a **Special Needs Trust**. Some of the principles and concepts are similar to a variety of trusts created to protect the estates of the aging and elderly, which can be extremely useful information as many parents of children with disabilities are also concerned about their aging parents.

**Defined:** A **Special Needs Trust** (SNT) (sometimes called a **Supplemental Needs Trust**) is a specialized legal document designed to benefit an individual who has a disability. A SNT is most often a “stand alone” document, but a SNT can be created by, or be a part of, a Last Will and Testament.

A Special Needs Trust is a discretionary trust that allows a trustee to use trust funds to *supplement, not replace, a beneficiary’s government assistance*. The primary goal of a SNT is to maintain eligibility for certain needs-based supports (ex. Medicaid) while providing funds to support the beneficiary for a fuller and more satisfying life.

### Important General Characteristics:

- The beneficiary cannot have direct control over the funds (assets)
- The beneficiary cannot manage the assets
- The use of the funds are strictly for the benefit of the beneficiary as determined by the discretion of the Trustee
- Income taxes may apply to income and distributions on the accounts from the date that the trust is funded. However, it is important to remember that **taxable income** is not necessarily “countable income” for purposes of Medicaid or other government supports. [More information.](#)

In a nutshell, a *beneficiary* of a properly drafted Special Needs Trusts does not have legal claim to the property (including cash) in the trust. That means that the trust's assets are not countable resources and therefore do not affect the beneficiary's eligibility for assistance and supports. The beneficiary is able to receive governmental assistance, while using the resources in the trust to supplement expenses such as therapies, certain living expenses, transportation, and other qualified expenses.

To maintain eligibility for governmental assistance and supports, SNT **funds cannot be used for basic support items such as medical care, food, clothing, or shelter**. Medicaid, SSI, or Social Security Disability Insurance (SSDI) should cover these costs. However, it is important to note that sometimes it is advantageous to the beneficiary to use funds from the SNT in a way that reduces assistance or incurs penalties. That is a judgment call every beneficiary and trustee may have to make to ensure the beneficiary is living the best possible life.

With the exceptions listed above, funds in a Special Needs Trust can be used for just about anything the government doesn't pay for, including rehabilitation and medical care not covered by public benefits, education and training, transportation, insurance, accessible vehicles or general transportation, and home modifications. In addition a SNT can pay for quality-of-life expenses such as travel, recreation, hobbies, and entertainment.

**Special Needs Trusts are not self-directed accounts.** The trustee has a fiduciary responsibility to protect the funds in the trust and ensure that the funds are used properly in accordance with applicable regulations and laws. This sometimes creates friction between beneficiaries, but is an essential characteristic of a SNT that cannot be altered.

For more info: [What Is a Special Needs Trust?](#)

### **Types of Special Needs Trusts:**

There are three types of special needs trusts that are most used for people with disabilities.

#### **A First Party (or Self-Settled) Trust, a Third-Party Trust, and a Pooled Trust.**

Each one has specific advantages and disadvantages and must be properly tailored to fit the individual with a disability and meet the needs of the individual's family.

#### ***First Party (Self-Settled) Trusts***

A **first-party or Self-Settled SNT** may be desirable when a person with a disability *has assets, or expects to receive assets* that would disqualify him or her from receiving services, assistance, or supports. These types of trusts are typically used when:

- Settling a lawsuit *after which* the individual requires governmental supports (personal injury, malpractice, or other wrongful action)
- Receiving an inheritance for a person who already has a disability

- After a divorce settlement in which one party must pay either a lump-sum or monthly supports to a spouse with a disability

**First-party SNT Characteristics (includes SNT general characteristics):**

- Must be established by a parent, grandparent, guardian, or a court
- The trust must be "irrevocable," (not cancelled or rescinded)
- The beneficiary's assets (only) must be used to fund the trust
- The beneficiary must be under age 65 at the time the trust is established

**Advantages and Disadvantages:**

The primary advantage of the first-party trust is that this type of trust allows a *beneficiary's own money* to be sequestered to retain benefits. And (in theory) a beneficiary has slightly more control over the distributions and how they are spent, as the grantor and beneficiary may be the same person. (Note: Some pooled trust are the only other trust options that have similar characteristics) However, the disadvantage is that all funds in the trust are available for the [Medicaid Estate Recovery Program \(MERP\)](#), which is a payback provision that reimburses the state for Medicaid expenses that were incurred during a beneficiary's lifetime.

***Third Party Trust***

A **third party SNT** is intended to hold assets *given or bequeathed* to a individual with disabilities by a **third party**, such as parents, grandparents, other family members, life insurance policy, or from almost any other source.

A **third party SNT** is typically designed as part of a family's estate plan to provide for a family member with a disability while the donor(s) are still living and to manage any inheritance(s) that a person with a disability may receive when a donor dies.

A donor can fund these trusts in a variety of ways including a direct transfer of funds (during life or upon death), transferring assets, or life insurance proceeds. Funds can include stock, real estate, other property, and cash.

**Third-Party SNT Important Characteristics (includes SNT general characteristics):**

- Funds or assets in the trust never belonged to the beneficiary
- Must be set up by donor (anyone but beneficiary)
- No age limit for the beneficiary
- No limit to the amount of money that can be put in a trust
- Upon the beneficiary's death, the assets in a third-party SNT can pass to the donor's other relatives or anyone else – even into another trust
- Costs to set up and manage the trust are extremely variable

- The trust may be "irrevocable," (most common) or not ("revocable"). However, a revocable trust may incur liability and be subject to the [Medicaid Estate Recovery Program \(MERP\)](#) provision.

### **Advantages and Disadvantages:**

One of the main advantages of the third party SNT is that if it is correctly structured, **third party SNT trusts *are not*** subject to [Medicaid Estate Recovery Program \(MERP\)](#) provision. The funds came from third-party donor, were never owned by the beneficiary, and are therefore exempt from MERP and can be gifted, transferred into another trust, or used in other ways in the event of the death of the beneficiary.

However, one of the major drawbacks of a third-party trust is a beneficiary *absolutely cannot* place their earned income or an inheritance that is paid directly to them into the account. *It is crucial that everyone who may be a donor to the individual with a disability name the third party SNT (not the individual) as the receiver of any donations or gifts.*

### ***Pooled Trusts:***

In Texas, Pooled Trusts were authorized in 1997 to address the most significant barrier to participation in SNTs by low-income families, which was the overall high costs of creating and maintaining a special needs trust. Pooled Trusts are typically managed by nonprofit organizations that keep separate accounting of individual beneficiary funds, but "pool" all of the funds to invest more efficiently and in order to maintain low services fees.

### **Pooled Trusts Characteristics (includes SNT general characteristics):**

- The beneficiary may be over or under age 65 at the time the trust is established depending on the specific plan
- Can be either third party trusts or self-settled trusts
- *Not* subject to [Medicaid Estate Recovery Program \(MERP\)](#) provision as long as the *funds are retained in the trust* for the benefit of other disabled beneficiaries
- Funds are subject to the to [Medicaid Estate Recovery Program \(MERP\)](#) provision if the funds were deposited directly from the beneficiary (their own money)

### **Advantages and Disadvantages:**

The advantages of the Pooled Trust are primarily the lower set-up and maintenance costs in a one-stop-shop environment, where many of the functions (payments, taxes, and investments) are performed by the manager of the trust. In some programs, a beneficiary can deposit earned income into the beneficiary's account, which is not allowed in a third-party SNT. This feature provides flexibility for people with disabilities who work and earn enough to have difficulties staying below the \$2,000 Medicaid asset cap. However, a Pooled Trust may be a mixed bag, as pooled investments may increase overall investment power, but eliminate the ability for trustees to manage individual account investments.

**For More Information:**

- Texas Young Lawyers Association - [Peace of Mind - 2011](#). TYLA’s document provides detailed information on topics such as: Individuals with Disabilities Education Act (IDEA), housing, employment, SSI and Medicaid, estate planning, and SNTs. Note that the guardianship information needs to be updated to reflect reforms recently passed that stress least restrictive alternatives to guardianship and supported decision-making (see grsdm.org).
- The [Academy of Special Needs Planners website](#): - A valuable resource with a great question and answer section
- Great detailed info from the [American Bar Association](#) providing a checklist and in-depth trust information
- SSA Program Policy Information Site contains the public version of the [Program Operations Manual System \(POMS\)](#)

-----

**Comparisons and Contrasts of ABLE and Special Needs Trusts**

The purpose of this report is to provide a strong foundation for individuals, and families of people with disabilities to make educated decisions about the best mix of financial life-planning options for their family. A Special Needs Trust has been chosen for comparison and contrast with an ABLE account, as they are the two most often used tools and have the most potential synergy to provide the most impact for a beneficiary. However, a Pooled Trust is a popular option due to the lower costs to set up and manage. Please refer to the section on trusts for more details.

The chart below highlights a few of the notable elements of both a Special Needs Trust and an ABLE account.

<b>Special Needs Trust</b>	<b>ABLE Account</b>
<ul style="list-style-type: none"> <li>• Not self-directed</li> <li>• Limits on disbursements are common</li> <li>• Managed by Trustee</li> <li>• Funds cannot pay for medical care, food, clothing or shelter</li> <li>• No max limit for funds</li> <li>• Trust drafted by lawyer</li> <li>• No MERP* lien for 3rd part, MERP* applies for 1st party</li> </ul>	<ul style="list-style-type: none"> <li>• Can be self-directed or not</li> <li>• Disbursements may be limited or unlimited (debit card options also)</li> <li>• Managed by Individual or Supporter</li> <li>• Broad expense categories</li> <li>• Deposits limits of \$14K/yr with \$370K maximum cap (TX)</li> <li>• Individual or Supporter can set-up an account online</li> <li>• MERP* applies, but may not be applicable in certain circumstances</li> </ul>

\*As a reminder, the [Medicaid Estate Recovery Program \(MERP\)](#) is a payback provision that reimburses the State that a beneficiary lives in for Medicaid expenses that were incurred during a beneficiary's lifetime.

### **ABLE and Trusts - Working in Unison**

An ABLE Account and a trust can be used in conjunction to provide better outcomes for the individual with a disability. For example:

- A Special Needs Trust cannot be used to pay for housing costs unless you incur penalties, which most trust managers are reluctant to do, as they have a fiduciary responsibility to oversee the funds in the best manner possible.
- An ABLE account can pay for housing costs with penalties or problems.
- ❖ Funds from a Special Needs Trust can be transferred to an ABLE Account to pay rent that a person with a disability might not be able to afford if they only receive Social Security income

- A Special Needs Trust may have unlimited funds deposited into the account, which is essential for inheritances, or if person receives substantial amounts of money from an insurance policy.
- An ABLE account cannot receive more than \$14,000 per year.
- ❖ Funds could be placed in a trustee-controlled Special Needs Trust and then transferred to the individual self-directed ABLE Account to ensure the person with a disability has more access to their own money with more flexibility in spending.

- A parent might direct when setting up a Special Needs Trust that funds are kept primarily in the trust in order to protect the individual from having access to all of their trust funds at one time.
- An ABLE Account could be used as a clearing account for the individual to transfer the amounts needed with a budget developed by the individual parents or supporter.
- ❖ The individual could have money for their personal needs while learning how to be responsible and how to manage their own money.

These are just three illustrations of how both tools can complement each other when used together. As people begin to use these accounts the expectation is that many more uses will be found for ABLE Account holders that will greatly expand their independence.

### **Recommendations**

As stated in the introduction, an **ABLE Account and a Trust both** have vast potential to provide much needed supplemental funds for persons with disabilities and should be considered as complimentary financial tools with a single mission. With careful trust tailoring and choosing the best ABLE plan to suit the individual or family's needs, both tools

can be valuable to assist a person with a disability to achieve financial security and to promote independence and community living.

It is not really a question of which one to choose, but rather, how to use each tool to reach goals that have been set by the individual or family. **Both tools complement each other** and can be valuable depending on an individual or family's financial resources and personal situations.

However, any savings plan is inherently about the future. Make sure that the needs of today are taken care of before funds are set aside for the future. The best estate/life plan is the one that creates as much independence and self-sufficiency as possible for the individual with a disability.

Inevitably, during lectures on estate/family planning, questions arise about the process of setting up Special Needs Trusts, and which ABLE program is best. It is difficult at best to answer these questions; however, it is suggested that the following guidelines and principles can be helpful in this process:

When **finding a lawyer or a trust manager**, it is best to:

- Find someone you can **TRUST!** Ask other parents, or find someone by word-of-mouth.
- Make sure that they have drafted Special Needs Trusts before and are knowledgeable in the process and current laws for YOUR state.
- If they are not involved with the disability community in some way (volunteer, supporter, board member, family member) it might be best to find another person.
- Go with your instincts. If the person does not use “people first language” or something seems amiss, it might be best to find someone else.

When choosing an **ABLE Account**

- Be cautious when choosing a program, as they are all very new.
- Pay attention to the management fees and investment structures.
- Make sure the plan fits your needs.
- Plan when to fund the account. Don't fully fund the account on January 1<sup>st</sup> if you might receive funds during the year that will put you over the maximum cap of \$14,000.
- Weigh risks of having an account vs. ease-of-use and potential for independence. With responsibility comes risk, which is a large part of self-direction and independence.
- Don't save for tomorrow at the expense of today. If a child needs a specific expensive therapy, make sure they are getting that help rather than sequestering money that they may not be able to fully use sometime in the future.

One thing to consider is that other states may open ABLE programs very soon. There may be more competition with a wider variety of features as the programs develop. The ABLE

Act has already changed at a dramatic rate. Watch for changes and adjust your estate/life plan to match those changes.

**For More Information:**

- [Achieving Independence: A Guide to Creating an Estate Plan Which Ensures Quality of Life for You and Your Loved One with a Disability](#) - Stephen W. Dale Esq. Self-published. via <http://dalelawfirm.com/>
- [The Complete Guide to Creating a Special Needs Life Plan: A Comprehensive Approach Integrating Life, Resource, Financial, and Legal Planning to Ensure a Brighter Future for a Person with a Disability](#) – Ha Wright CFP.
- [Estate Planning in Texas: What you Need to Know](#) – Thomas J. Daley.

**Policy Recommendations**

Governmental advocacy for people with disabilities is absolutely an important agent of change. The American's with Disabilities Act and the ABLE Act are examples of the successes for grassroots advocacy. While researching and writing this report, several areas for improvement became evident and are listed below.

## Federal recommendations:

- The Medicaid asset cap must be raised in order to allow people with disabilities to have the chance to live full and included lives. [H.R. 2442](#) and [S. 1387](#), the *Supplemental Security Income Restoration Act of 2015*, both address the asset cap (among other SSI issues). These bills should be supported or another bill should be filed to raise the individual asset cap to \$10,000 and the couples cap to \$20,000. This would provide individuals with disabilities who are employed to be more fully employed and possibly eliminate the need for governmental services and supports for some. For More Information: [Asset Limits Are a Barrier to Economic Security and Mobility](#)
- The ABLE Act Improvement Bills (H.R. 4794, 4795, 4813 & S. 2702, 2703, 2704), referenced in the ABLE Act section, should be supported. In addition, other pending bills ([Special Needs Trust Fairness Act – H.R. 670](#)) related to financial independence should be supported.

## For People with Disabilities:

- Individuals (in particular youth) with disabilities must be provided with quality high-quality financial literacy training as either a part of transitions services, in college programs, or in other venues. It is imperative that individuals have the basic (and advanced) budgeting skills and the ability to understand the value and uses of money. Programs must be tailored to the needs and abilities of all individuals.
- Information on the ABLE Act and the available programs should be fully incorporated into transition planning at public schools, at state agencies, and for vocational rehabilitation providers.

- Information about the ABLE Act and the available programs should be added to the list of alternatives to guardianship as a support tool.

## Acknowledgements

Without the generous support of the Texas Council for Developmental Disabilities, this report would not exist. In addition, CTD staff and mentors have helped guide this research to truly focus on self-determination and independence. Many others contributed in a variety of ways including: Stephen W. Dale Esq., Erin Lawler, Texas Comptroller of Public Accounts and the incredible staff of the Educational Opportunities and Investment Division. Senator Charles Perry, Matthew Dowling, Representative Cindy Burkett and her staff, the El Paso Youth Leadership Forum, hundreds of parents, siblings, and allies who saw the potential in ABLE and gave a vast amount of input and guidance at lectures and workshops. Members of the Texas ABLE Advisory Committee, and the supporters who helped pass SB 1664 during the 84<sup>th</sup> Texas legislative Session:

Access College Texas • ADAPT • Association of Centers for Independent Living (TACIL) • Austin Resource Center for Independent Living (ARCIL) o Austin, San Marcos, & Round Rock • Autism Society of Central Texas • Autism Speaks • Center for Public Policy Priorities (CPPP) • Coalition of Texans with Disabilities • Coastal Bend Center for Independent Living • Community NOW! • "Down" By The Border • Down Syndrome Association of Central Texas (DSACT) • Down Syndrome Guild of Dallas (DSG) • Easter Seals of Central Texas • National Down Syndrome Society • RAISE Texas • REACH Resource Centers on Independent Living o Dallas, Ft. Worth, Plano, & Denton • Texas Association of Goodwills • Texans Care for Children • Texas Down Syndrome Advocacy Coalition of Texas • Texas Parent to Parent • Texas Public Policy Foundation (TPPF) • United Ways of Texas • Valley Association for Independent Living (VAIL) o Rio Grande Valley, & McAllen • Volar Center for Independent Living (VOLAR)

A project of the Texas Council for Developmental Disabilities.

Disclaimer: *The views contained herein do not necessarily reflect the position of the funding agency(s).*

Financial Support for the CTD Developmental Disabilities Policy Fellowship is provided by the Texas Council for Developmental Disabilities, with Federal funds\* made available by the United States Department of Health and Human Services, Administration on Intellectual and Developmental Disabilities. \*\$67,500 (71%) DD funds; \$27,011 (29%) non-federal resources.

