

Pennsylvania Message

ABLE Accounts: One Path to A Better Life

The Achieving a Better Life Experience Act (ABLE) Act, signed into federal law in December 2014, creates a more just system for people with disabilities. It gives people with disabilities the right to save money that can be used for community living expenses. ABLE accounts allow individuals with disabilities to save money beyond the previous \$2,000 asset limit; these funds can be used for community living expenses and, with some exceptions, do not affect an individual's eligibility for Social Security or Medical Assistance. ABLE accounts can be used for short-term or long-term needs, and it is expected that many people with disabilities will use them as a transaction account with money going in and out on a regular basis.

ABLE accounts improve a system that previously discouraged people with disabilities from working, saving money, and improving their financial stability. It is the first mechanism the United States will have that allows people with disabilities to take their own money from employment and save for long-term living expenses that Medicaid does not cover, such as education beyond high school, transportation, or housing. The spirit and intent of the ABLE Act is to provide people with disabilities the freedom and choice that all citizens have—to plan for their future and to seek as much economic self-sufficiency as possible. According to the federal ABLE act, the owner of the account must be the person with a disability who is also the beneficiary of the funds in the account.

Our own Senator Bob Casey and Sara Wolff, Board Director, The Arc of PA, were instrumental in ensuring that the ABLE Act was passed. It took over seven years and the tireless work of numerous advocates with and without disabilities, family members, and legislative champions to make the ABLE Act law.

In order for the ABLE Act to pass, numerous changes and compromises occurred. One example is that the finalized version of the ABLE Act includes tighter restrictions on who is eligible for ABLE accounts (specifically, individuals whose disability occurred before age 26).

Each state must decide whether to give their residents access to ABLE savings accounts by passing legislation that sets up ABLE accounts in the state. There are currently bills in the PA Senate and House that would establish ABLE Accounts in Pennsylvania. Some states, including Pennsylvania, plan to allow residents of other states to open an ABLE account in the state. More detail on the ABLE bills currently being considered in Pennsylvania is on page 5.

The Federal government recently shared draft regulations for ABLE accounts that individuals and groups, including The Arc of PA, are commenting on. These regulations give instructions to Pennsylvania on rules that ABLE accounts must follow. See our article on page 7 for more details about these proposed regulations.

President's Message - Ken Oakes



Standing on the Shoulders of Giants

Thirty-nine years ago I was fortunate to land a summer job in the school division of The Gertrude Barber Center in Erie, my hometown. I was just beginning my studies in special education at Mercyhurst College. Little did I know at the time that the summer of 1976 would change my life forever.

When I began work that summer, I had never even heard of The Arc, or what was so big then, the Youth Arc movement. Soon I became active in both The Arc and Youth Arc of Erie County, making some great and lifelong friends, serving children and adults with intellectual disabilities, and beginning to develop my advocacy and leadership skills.

I was fortunate to meet some tremendous leaders in the Arc “family”. Gertrude Barber, Irene Smerick, Jean Isherwood, Eleanor Elkin, Jim Wilson, Teddi Leiden, Dennis Hagarty, Pat Clapp, Marsha Blanco and more people than I could ever list here. I never imagined that one day I too would have the honor of serving as the president of The Arc of Pennsylvania.

The people I met were giants. They opened school house doors, closed institutions, created opportunities for people with intellectual disabilities to live and work in their own communities, and laid the groundwork for The Arc of PA to become one of the oldest, largest, and most influential family disability advocacy organizations in the state and nation.

In 1976 I did not realize that I was not only in the presence of great and insightful leaders, but that they would one day allow me to stand on their shoulders. The shoulders of giants. I only wish now that I could thank them all in person for what they did for countless children and adults with intellectual and other developmental disabilities and their families, and for me. I owe much of who I am today to my many mentors and friends.

As I begin my term as president of The Arc of Pennsylvania, I promise you that I will work as hard as I can to keep this organization strong, to expand the rights of our members and constituents, and to keep the hopes and dreams of so many alive and real.

Thank you for giving me this opportunity, and many thanks for letting me stand on your giant shoulders today.

A handwritten signature in black ink, appearing to read 'Ken Oakes', with a stylized flourish at the end.

*“To whom much is given, much is required –
not expected, but required.”*

– Andrew Young

Ken Oakes recently became the new President of The Arc of Pennsylvania.



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Executive Director’s Message Maureen Cronin

People With Disabilities Need A Budget



Earlier this year we devoted an issue of this newsletter to the state budget, how it affects people with disabilities, and what you can do to let legislators know its importance. We remain committed to advocating for a budget which values people with disabilities, but lawmakers have still not come to a decision over the budget. The Governor and the General Assembly submitted very different budgets and have not come to any compromise on passing a budget. There is little sign that this is going to change any time soon. In fact, the General Assembly went on break from June 30 until late August.

That has created an urgent problem - vital human services are not being funded. These services and the people who depend on them are hurting now. We need our elected officials to give our state budget the attention, time, and urgency it deserves. People with disabilities cannot wait.

As much as we would like a budget to pass soon, we also want to make sure that budget is fair to people with disabilities. The budget sent to Governor Wolf by the General Assembly would have hurt Pennsylvanians with disabilities. Pennsylvania needs sufficient funding for special education, employment opportunities for people with disabilities, and critical supports that would ultimately save Pennsylvania money by allowing individuals with disabilities to live in their homes and communities.

Compounding the effects of this budget impasse is the fact that funding for disability services in Pennsylvania has been unacceptably low over the past decades. Pennsylvania has 14,000 people with intellectual and developmental disabilities waiting for services, with about a third of these individuals in dire emergency situations. There are thousands of young adults with disabilities who aren’t working but could be, with the right supports. This is a serious injustice to people who are in need of the programs and services. Pennsylvanians with disabilities deserve a budget that adequately funds the services which help them fully participate in their communities.

We will continue advocating for a budget that values our most vulnerable citizens. Families, caregivers, and people with disabilities are struggling, and Pennsylvanians need our lawmakers to get to work ending this budget impasse. You can help by contacting your Senators and Representatives and telling them that we can’t wait. Let them know that you want to see a commitment to improving the lives of people with disabilities now and in the future. People with disabilities matter. You matter. Let yourself be heard.

Frequently Asked Questions About ABLE

Do I qualify for an ABLE Account?

Individuals are eligible for ABLE Accounts if their disability began before age 26. Details about what information people with disabilities will have to provide in order to open an ABLE account are still being determined.

How do I get an ABLE Account?

The Pennsylvania Treasury Department and legislators are currently working to make ABLE accounts available in Pennsylvania, so it is still unclear where you will go to sign up for an ABLE account. We expect ABLE accounts to be overseen by the Pennsylvania Treasury Department. The article on page 5 gives more detail about where Pennsylvania is at in establishing ABLE accounts. You can go to pa529.com/able.html, run by the Pennsylvania Treasury Department, and sign up to receive notices about ABLE accounts.

Will opening an ABLE Account hurt my Social Security or Medicaid services?

Funds in an ABLE account will not be counted when considering if you qualify for Medicaid. The first \$100,000 in an ABLE account will not be counted in considering your eligibility for Social Security; any amount above \$100,000 in an ABLE account will be considered when determining your eligibility. If you put more than \$100,000 in an ABLE account, your Social Security payments would be decreased or suspended; once your ABLE account balance fell back to \$100,000 or below, your Social Security payments would be reinstated.

What is the cost of opening an ABLE account?

One of the anticipated benefits of an ABLE account is that it will be low cost to open and maintain. Since Pennsylvania is still deciding how ABLE accounts will be structured in the state, it is not yet clear how much the opening cost and yearly fees of the account will be.

How much money can I save in an ABLE account?

The limit to how much can be put into a person's ABLE account each year is the IRS gift limit for the year, which for 2015 is \$14,000. Each state puts a limit on how much total money can be put in an ABLE account, typically based on the existing limits for 529 college savings accounts. In Pennsylvania, that limit is \$452,210 for 2015.

Who can put money into an ABLE account?

Anyone can put money into an ABLE account—that includes the person with a disability who owns the ABLE account, family members, and friends.

What can I spend money from an ABLE account on?

Money can be withdrawn from ABLE accounts and spent on community living expenses like education, housing, transportation, employment training and support,

assistive technology and personal support services, health, prevention and wellness, financial management and administrative services, legal fees, expenses for oversight and monitoring funeral and burial expenses, and other expenses. **If ABLE funds are used for housing expenses, this will impact Social Security payments but not Medicaid benefits.**

It is also important to know that there will be penalties if funds from an ABLE Account are used for non-qualified expenses. If money from an ABLE account is spent on a non-qualified expense, income tax and possibly a 10% fee would be charged on that withdrawal.

What is the difference between an ABLE account and a special needs trust?

The article on page 8 gives more detail about this. In general, ABLE accounts are less costly to set up than trusts; are tax-free accounts; have more stringent restrictions on eligibility and the amount of money that can be put into the account than trusts; can give a person with a disability more control over the account than a trust; and may be claimed by the state to pay back Medicaid, unlike most special needs trusts.

Can I have multiple ABLE Accounts?

Because of how the federal ABLE Act is written, individuals can only have one ABLE account. While ABLE accounts are modeled on 529 College Savings accounts, this is one important difference between ABLE accounts and 529 accounts.

What happens to money left in a person's ABLE account if the person passes away?

Money remaining in an ABLE account after a beneficiary (person with a disability) dies will be used to pay back Medicaid. The state will be able to go through a process and claim remaining ABLE funds. You can set up an ABLE account to transfer ownership to a sibling, if that sibling is eligible for an ABLE account.

Where should I go to talk about long-term care planning options so I can consider ABLE accounts, special needs trusts, and other financial planning opportunities?

The Arc US has a wonderfully accessible site, futureplanning.thearc.org, that explains the basics of how to begin planning for the future of a person with disabilities with a focus on financial planning. It includes advice for people with disabilities, parents, other family members, and advocates. Lawyers that specialize in special needs trusts are also learning about ABLE accounts and how they can complement financial planning for people with disabilities.

State ABLE Bills – Where They’re At, How They’re Different

Pennsylvania is fortunate to have so many legislators that care about making ABLE savings accounts available in the Commonwealth. The Arc of Pennsylvania recognizes and appreciates Senators Baker, Tartaglione, and Dinniman and Representatives Stephens, Miller, and Marshall for introducing bills that would make ABLE accounts accessible in Pennsylvania; their commitment to Pennsylvanians with disabilities is evident. Since each state must decide if and how to offer ABLE accounts, Pennsylvania must pass legislation authorizing ABLE accounts before they can be available here.

Currently bills SB 879 (introduced by Senator Lisa Baker R-Luzerne) and HB 1319 (introduced by Representative Jim Marshall R-Beaver) are moving in the General

Assembly. It is in the interest of Pennsylvania that whichever ABLE bill passes applies the federal law and regulations as broadly as possible so that no state-imposed regulations restrict the use or implementation of ABLE accounts. This will also prevent Pennsylvania from having to significantly change ABLE accounts in the state if future changes improve ABLE accounts.

Representatives Miller and Stephens and Senator Tartaglione started the conversation on ABLE bills in Pennsylvania with the legislation they introduced, and elements of these bills have been included in the bills HB 1319 and SB 879 that are currently moving in the House and Senate. See the chart below for a comparison of the ABLE bills in our state legislature.

Comparison of ABLE Bills - Legislative Status		
Bill Number	Prime Sponsor	Current Status
HB 444	Rep Todd Stephens (R-Montgomery)	Superseded by HB 1319, In House Finance
HB 583	Rep Dan Miller (D-Allegheny)	Superseded by HB 1319, In House Finance
HB 1319	Rep Jim Marshall (R-Beaver)	Passed out of the House nearly unanimously 6/24/15; In Senate Finance
SB 726	Senator Tartaglione (D-Philadelphia)	Superseded by SB 879 and HB 1319; In Senate Finance
SB 879	Senator Lisa Baker (R-Luzerne)	Passed unanimously out of Senate Finance 6/24/15; In Senate Appropriations

Comparison of ABLE Bills - Effect on Government Roles			
Bill Number	Role of PA Treasury Department	Reporting Requirements	Medicaid Payback
HB 444	Allows Treasury Department to offer and regulate ABLE savings accounts in PA; Allows Treasury Department to contract with program managers to assist in investment; Creates separate ABLE Bureau within Department of Treasury	Creates ABLE Advisory board that reports annually to Governor	Relies on federal law
HB 583	Allows Treasury Department to contract with financial entities as account managers and depositories	Treasury Department must provide annual evaluation report on ABLE accounts in PA to the Governor and General Assembly	May be claimed by state Medicaid agency
HB 1319	Allows the Treasury Department to offer and regulate ABLE savings accounts in PA	Department must submit annual performance report to Governor, relevant committees, and account owners/beneficiaries	Relies on federal law
SB 726	Identical to HB 444	Identical to HB 444	Identical to HB 444
SB 879	Allows Treasury Department to offer and regulate ABLE savings accounts in PA using the Tuition Account Program structure already in place in the Department without completing a bidding process for program management	None stated	Relies on federal law

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Comparison of ABLÉ Bills - Effect on Individuals

Bill Number	Control of ABLÉ Account	Allowable Uses	Allows Individuals to Open ABLÉ Account in Another State	How Eligibility is Determined	Waiting Period for Using ABLÉ Funds?
HB 444	Account owner receives remaining ABLÉ funds after death of beneficiary; account owner is defined as the person/entity who opens the account; beneficiary is the person with a disability on whose behalf the account is opened	Relies on federal regs for definition of qualified expense	No	Relies on federal regs	Yes, One year waiting period between when funds are deposited in ABLÉ accounts and when they can be withdrawn, unless otherwise determined by Board or Treasury Department
HB 583	Account owner can be person with a disability or the guardian of a person with a disability	Relies on federal regs for definition of qualified expense	Yes. Also codifies having only one account as a state regulation of ABLÉ	Relies on federal regs	No
HB 1319	Designated beneficiary is the person whose expenses are paid from the ABLÉ Account. Account owner is defined as the person who opens the account and who is permitted to be the account owner under federal regulations (person with a disability is the "account owner" insofar as the Federal Regulations require this)	Qualified expenses include but are not limited to the following: Education. Housing. Transportation. Employment training and support. Assistive technology and personal support services. Health, prevention and wellness. Financial management and administrative services. Legal fees. Expenses for oversight and monitoring. Funeral and burial expenses.	No. Residents of other states can open ABLÉ accounts in PA if PA contracts with that state, but PA residents cannot open an ABLÉ account in other states.	Codifies disability certification process in state law (instead of only leaving it up to federal regs)	No
SB 726	Identical to HB 444	Identical to HB 444	Identical to HB 444	Identical to HB 444	Identical to HB 444
SB 879	Person with a disability is the "account owner" insofar as the Federal Regulations require this. Allows parents, guardians and others to open ABLÉ account on behalf of person with a disability	Relies on federal regs for definition of qualified expense	Yes. Allows Pennsylvania residents to open an ABLÉ Account in another state, and vice versa	Relies on federal regs	No

ABLE Regulations: Why They Matter and How To Comment

The Social Security Administration and IRS recently released draft ABLE regulations that would determine how ABLE accounts work in each state.

You can read the proposed regulations at:
www.regulations.gov/#!documentDetail;D=IRS-2015-0030-0001

Comment on the proposed regulations at:
www.regulations.gov/#!submitComment;D=IRS-2015-0030-0001

These regulations matter because they will impact how affordable it is to open and maintain an ABLE account in Pennsylvania; how and what type of information an individual will have to provide to show eligibility for an account; and how easily individuals can withdraw and use money from the ABLE account.

We support the following aspects of the proposed ABLE regulations:

The draft regulations propose that ABLE accounts must make the person with a disability both the account owner and beneficiary of the ABLE account. The regulations also allow family members who either have power of attorney or are legal guardians to open an account on behalf of a person but must not benefit from being a signatory on the account. The Arc of Pennsylvania supports this because it is empowering for an individual with a disability to have ownership over a bank account. Additionally, people with disabilities who have competitive, integrated employment that have money from their paychecks should be able to save this money in their own account. The regulations also take into account families who have young children and others who want to ensure they have access to ABLE accounts by allowing a family member to open an account on behalf of the individual with a disability.

In the proposed regulations a “qualified disability expense”, which is what money from an ABLE account is allowed to be spent on, is interpreted quite broadly to include expenses that improve health, independence, and quality of life. We agree that a qualified disability expense should be interpreted as broadly as possible so that people with disabilities have as much freedom as possible to use funds from ABLE accounts for expenses that are vital for living in the community.

The draft regulations propose that an ABLE account could, after the individual who owns the account dies, be given to a sibling who is eligible for an ABLE account. Funds could also be given to another designated eligible individual who is not a relative, subject to a gift or transfer tax. We support designation of another beneficiary because if the individual who dies does not have a sibling eligible for

ABLE accounts, any remaining money in an ABLE account would be subject to estate tax and Medicaid payback. The proposed regulations inclusion of choice to leave ABLE funds to another eligible person would give an individual another option for deciding where the money remaining after their death should go.

Under the proposed regulations, individuals can keep their ABLE account open in the state they started the account if they move. They do not have to transfer their ABLE account to another state if they move. We support this because it reduces the burden on individuals with disabilities and their families.

We are concerned and want to have more information about the following:

Under the proposed regulations states have some control over what evidence is required to determine eligibility if person claims eligibility because they are eligible for SSI and have a disability that occurred before age 26; alternatively, individuals can submit a “certification” that they have a disability that occurred before age 26 that must be signed by a doctor. Additionally, annual recertification of eligibility is necessary but states can determine how they will meet this requirement. We are concerned about this requirement because we want to ensure that this process is as streamlined and expeditious as possible so that it is not burdensome for people with disabilities. We are concerned that requiring the states to be responsible for eligibility certification will create an administrative burden that either deters states from operating ABLE accounts and/or adds to the cost of administering ABLE accounts.

The proposed regulations suggest that any money from a person’s ABLE account that is used for an “unqualified” expense should be included in the person’s gross income, subject to income tax, and receive a 10% penalty that the person would have to pay. The proposed regulations do not give guidance as to how a state will know if an expense is “unqualified”.

We do not support the additional 10% fee on non-qualified ABLE withdrawals because it would put a further and unnecessary burden on an individual who mistakenly uses ABLE funds for a non-qualified expense. Additionally, more information is needed on how qualified and non-qualified expenses will be determined. A lengthy determination process for qualified withdrawals would not be in the interest of people with disabilities. We are concerned that the administrative requirements put onto state ABLE programs by these proposed regulations will be detrimental to the cost-effectiveness and responsiveness of ABLE accounts.

Special Needs Trusts and ABLÉ Accounts

Disclaimer: The Arc of Pennsylvania cannot offer financial advice. Please seek the advice of a professional familiar with special needs trusts for questions about long-term financial planning.

ABLE accounts and special needs trusts have important similarities and differences. Both ABLE accounts and special needs trusts provide a way for people with disabilities and their families to put money aside to help provide for an individual with a disability without impacting that person's eligibility for benefits. It will depend on an individual's unique situation which type of account is the best fit for long-term financial planning.

In general, special needs trusts do not have as narrow of an age restriction as ABLE accounts and allow for a broader range of purchases; they also do not have limits on annual contributions or how much money can be in

the trust. Special needs trusts can be costly and complex to set up and oversee.

There are different types of special needs trusts that are known by various terms. "Pooled" trusts and "individual" trusts have different structures, and a trust can be "first party" or "third party". For this article we will refer to these different special needs trusts as "first party", "third party", "first party pooled", and "third party pooled" special needs trust. All trusts can and should be set up so that they do not impact an individual's eligibility for Medicaid, SSI, or other important benefits.

A first party trust is a type of individual trust that is set up by a family member or guardian to benefit a person with a disability. The trust must be funded by the person with a disability, such as with money from an inheritance. There are no restrictions on how much money can be

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Comparison of ABLE Accounts and Special Needs Trusts¹

Type of Account	ABLE Accounts	Special Needs Trusts			
		First Party		Third Party	
		Pooled	Individual	Pooled	Individual
Set up by	Person w/ disability Family	Person w/ disability or Family	Family	Family	Family
Funded by	Person w/ disability (e.g. work income) Anyone else	Person w/ disability (e.g. inheritance money)		Family or anyone (but NOT the person w/ disability)	
Administered by	Individual and family; emphasis on allowing the person w/ disability to control use	Non-profits	Trustees	Non-profits	Trustees
Setup Cost	Undecided but should be less than trusts	Varies; can be costly and complex			
Interest Taxed?	No	Yes	No	Yes	Yes
Deposit Restrictions	IRS Yearly Gift Limit (\$14,000 in 2015)	None			
Balance Restrictions	Over \$100,000 cannot receive Social Security; absolute limit based on 529 savings account limit (\$452,210 in 2015)	None			
Age Restrictions	Person must have disability by age 26	None	Must be set up by age 65	None	
Other Restrictions	Funds can only be used on qualified expenses. Penalties if used for unqualified expenses.	None, but certain distributions could impact benefits.			
After death	Can be transferred to qualified siblings or to another designated qualified individual. Otherwise it pays back Medicaid and the state can claim the remaining balance.	Transfers to Non-profit to benefit others individuals with disabilities or pays back Medicaid	Pays back Medicaid	Can transfer to other named beneficiaries	

¹ <http://www.tba.org/journal/an-alternative-to-a-special-needs-trust-the-able-account>

put in the trust. The money earned from interest in this trust is taxed. It has to be set up before the person with a disability turns 65, and after the individual dies the money from the trust can be claimed by their state of residence to pay back Medicaid costs.¹

A third party trust is a type of individual trust that is set up and funded by anyone besides the individual with the disability. There are no restrictions on how much money can be put in the trust. The money earned from interest in this trust is taxed. After the death of the individual with a disability, money remaining in this trust can go to any beneficiary named in the trust—it does not have to be used to pay back Medicaid.²

Pooled trusts are administered by a non-profit organization. For instance, in Pennsylvania ACHIEVA runs the ACHIEVA Family Trust and The Arc Alliance, The Arc of Chester County and The Arc of Delaware County help lead The Arc Community Trusts of PA. They can be set up by an individual with a disability or a parent/legal guardian. Money earned from interest income in a pooled trust is taxed. They are an alternative to individual special needs trusts, typically providing a less expensive and less complex method of opening a trust than individual trusts. Non-profits will also usually manage a trust that has any amount of money in it, whereas sometimes it is difficult to find a professional trustee to manage an individual trust without having a significant amount of money in the trust.³

Funds remaining in a pooled trust after the death of the

individual with a disability are typically either retained by the managing non-profit organization and used to benefit other people with disabilities or claimed by the state for Medicaid payback.⁴ A pooled trust can be set up so that only the assets of the person with a disability go into the trust (first party) or funds from anyone else can go into the trust (third party). A non-comprehensive list of available pooled trusts is available at <http://specialneedsanswers.com/pooled-trust>.

A first party pooled trust is a trust that is funded by the assets of a person with a disability. There is no age restriction on setting up a first party pooled trust. After the individual with a disability dies, money left in this trust typically goes to the non-profit organization that administrates the trust to use for the benefit of other individuals with disabilities or is claimed by the state as Medicaid payback.⁵

A third party pooled trust is a trust that is funded by sources other than the person with a disability. There is no age restriction on setting up a third party pooled trust. After the individual with a disability dies, money left in this trust can go to other beneficiaries named in the trust instead of being used to pay back Medicaid.⁶

ABLE accounts are unique in that they are the *only* savings account that can be opened and owned by a person with a disability and whose interest income is not taxed. ABLE accounts create a mechanism for people with disabilities who are working to manage their own savings account by directly putting money into the account.

1 <http://specialneedsanswers.com/what-is-a-first-party-specialneeds-trust-and-when-is-it-useful-13264>

2 <http://www.specialneedsalliance.org/the-voice/your-specialneeds-trust-explained-2/>

3 <http://www.specialneedsalliance.org/the-voice/using-pooledtrusts-in-estate-planning-2/>

4 <http://www.specialneedsalliance.org/the-voice/using-pooledtrusts-in-estate-planning-2/>

5 http://www.americanbar.org/publications/bifocal/vol_34/issue_5_june2013/pooled_trusts.html

6 http://www.americanbar.org/publications/bifocal/vol_34/issue_5_june2013/pooled_trusts.html

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Stay Informed with PIE - The Policy Information Exchange (PIE) covers policy issues for Pennsylvanians with disabilities, their families, and advocates. The Arc of Pennsylvania manages PIE for the PA Developmental Disabilities Council.

Email us at pie@thearcpa.org to receive electronic alerts and the quarterly newsletter.

GO GREEN

The Pennsylvania Message is now available via email. Please send your full name, local chapter, and email address to ahouser@thearcpa.org to receive your electronic copy.

Interview with Sara Wolff, A Champion of the ABLÉ Act



Senator Bob Casey and Sara Wolff

Sara Wolff is a champion of the federal ABLÉ Act who advocated over four years to support its passage. She has been involved with The Arc since 2004 and is a Board Director of The Arc of Pennsylvania and Secretary of the Board of The Arc of Northeastern Pennsylvania. Sara is also a Board Director of the National Down Syndrome Society (NDSS). She is an experienced public speaker whose passion comes from a strong family support system that make inclusion a priority from her birth through high school and college. Our Policy Director Ashlenn Masland-Sarani interviewed Sara to get an insider's view on what it took to help ABLÉ pass and why ABLÉ accounts matter.

Ashlenn: When did you first start advocating for the ABLÉ act?

Sara: I became a Board Director of the National Down Syndrome Society (NDSS) in 2007. I learned about the ABLÉ Act and what it means and stands for and what it can do for people. I actually started advocating for it in 2009. I was invited to lobby by Sara Weir, President of NDSS. At the time Senator Casey was the main cosponsor of the ABLÉ act. Representatives Crenshaw, Sessions, and Morris-Rodgers were a huge part of getting the ABLÉ Act going.

Ashlenn: Why did the ABLÉ act matter to you? Why did you think it was important?

Sara: I think that people with all different kinds of disabilities have something they need to save money for so if someone passes away, if family members pass away, they can pay for things like transportation and medical costs. I happen to be one of those people. People with disabilities need to live in society to be safe and there are costs that go along with that.

Ashlenn: What was the most difficult part and most memorable part of getting the ABLÉ act passed?

Sara: Trying to get more co-sponsors was hard. How things run in the government are so complicated so it is hard to get people to not only support the bill, but to co-sponsor it. We worked hard on getting the Finance Committee to support the bill. One of the most memorable moments in advocating for ABLÉ was testifying at the Senate Finance Committee. That is still available online. (<https://www.youtube.com/watch?v=RS6KsqifLe0>)

Ashlenn: Tell us about starting the ABLÉ Act petition, which became one of the site's most successful petitions.

Sara: I wanted to get people's attention about the importance of the ABLÉ Act. I did a petition on Change.org to Congress and our senators, and it went viral. I didn't expect that many people to sign on. That petition helped tremendously to get the news about ABLÉ out. Al Jazeera news network picked it up. They did a piece on my life and the petition, and NDSS shared it on their social media. That's how it started.

Ashlenn: How did you feel when the ABLÉ act became law?

Sara: I was ready to party. That's how I felt. It had been so long we'd been working on ABLÉ. Stephen Beck and Sara Weir and champions in Congress had started this, and we got to see it pass.

Ashlenn: Who was the most interesting person you met while advocating for the ABLÉ act?

Sara: Senator Casey is now one of my coolest, closest friends. I interned in 2009 at Senator Casey's office after getting involved with the ABLÉ Act. The staff and board at NDSS are great. I also met the Vice-President, that was cool.

Ashlenn: What advice would you give people who see a problem in the community and want to do something about it?

Sara: I would tell them not to give up on their talents and dreams, to go for it. If you get in touch with The Arc, NDSS, or other advocacy organizations in your community, you could get better insights on things. There are many actions and events you can be involved with.

Ashlenn: What would you tell people who feel intimidated about talking to their legislators?

Sara: Don't be intimidated because legislators are there for you. Hearing your story is important to them. You shouldn't be scared because they need to hear those stories. You can find things to help you know how to meet your legislators. On the NDSS website and there are templates for how to speak to your representative and senator.



Sara Wolff talks with Senator Bob Casey at his office

Tech Talk: Are You Ready?

Emergency Preparedness, Assistive Technology and Persons with Functional and Access Needs.

By Jamie Arasz Prioli, RESNA ATP

September is National Preparedness Month and we want you to be prepared! Pennsylvania is no stranger to natural disasters such as flooding, fire, hurricane and tornado. People with disabilities, and especially people who use assistive technology, have unique needs when it comes to developing an emergency plan. Consider the following key points:

- Plan for the possible need to evacuate your home, school or workplace. Perform a personal assessment of the assistive technology (AT) you use. Identify what kind of resources you use on a daily basis and what you might do if those resources are limited or not available. What do you need to maintain your health, safety and independence? In addition, make sure you have what you need to stay where you are or “shelter in place”.
- Develop a list of AT used in your daily life. Do you use AT:
 - To assist you with mobility?
 - To help with your personal care?
 - To help you during meal time?
 - For communication?
 - For transfers?
 - For transportation?
 - For reading or listening?
- Learn how to send personal updates via text and internet from your mobile phone to your contacts and social channels in case voice communications are not available.
- Sign up for emergency emails and text messages from your local government alert system to get important information on your cell phone, in case you are deaf, hard of hearing, or not able access emergency notifications when they occur.
- Plan to make it on your own, at least for a period of three days. Compile a list of the AT critical to support your physical well-being and ability to communicate during an emergency. Have an appropriate back-up power supply and know how long the power supply lasts.

- Build an emergency “go kit” with your needs in mind. Your go kit should include items such as a battery or solar powered radio, flashlight, water and non-perishable food, power chargers for AT, copies of health insurance and identification cards, small denominations of cash, a list of emergency contacts and AT vendor information, AT serial numbers, and list of allergies to any drug or food.
- Think about how you might go about obtaining a short-term (or long-term) replacement for your AT, if needed. Contact Pennsylvania’s Initiative on Assistive Technology (PIAT) at 1-800-204-7428 (voice), 1-866-268-0579 (TTY), or email atinfo@temple.edu to find out about obtaining AT.

Being prepared for an emergency is crucial for you and your family, in your home, in your place of business or your school and throughout your community. “My Emergency Readiness Plan-PA” is an interactive form designed to help people with disabilities create personal plans to prepare themselves, their families and their supports for emergencies. Download the interactive form from our website: <http://disabilities.temple.edu/programs/eprep/>

For more information on emergency preparedness for individuals who use assistive technology and who have functional needs, contact PIAT at 1-800-204-7428 (voice) 1-866-268-0579 (TTY) or atinfo@temple.edu.

You can also visit the following resources on the web:

- Institute on Disabilities at Temple University
<http://disabilities.temple.edu/programs/eprep/>
- Reused and Exchanged Equipment Partnership (REEP)
<http://disabilities.temple.edu/programs/assistive/leep>
- Pennsylvania Emergency Management Agency
www.readypa.org
- Federal Emergency Management Agency
www.fema.gov
- American Red Cross
www.redcross.org



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Discovering Training Class



Marc Gold and Associates conducted a Customized Employment and Job Development Training for The Arc of PA Discovery Program in Harrisburg in July. The trainees are now equipped to connect Discovery program job-seekers with places of employment which are a good match for their skills, interests, and conditions for success. The event was organized by the Include Me/Discovery staff from the Arc of Pennsylvania and the training was taught by Mike and Teresa Callahan from Marc Gold and Associates.

MISSION STATEMENT

The Arc of Pennsylvania promotes the human rights of people with intellectual and development disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.