

The Arc.

Pennsylvania — Spring 2019 - Volume LVIII, Issue 2

Pennsylvania Message



President's Message Michael Marsh



Greetings!

Welcome to another issue of The PA Message. In this issue we are highlighting an important action taken by our Board of Directors at our March meeting - the adoption of a new position paper. The Arc of Pennsylvania Board of Directors unanimously approved the Technology position paper on March 9th as our call to action and statement of intentional support for the use of technology as a source of support for the people we serve. Technology has the power to level the playing field, improve our understanding of one another's needs, and be a platform for learning and fully participating in society.

My daughter is considered "non-verbal" in that she cannot (yet) speak words. She is now fourteen and one of the comments I have heard more than a few times is how difficult it must be to have a child who can't talk. While it is sometimes frustrating for her and for us when we don't quickly understand what is being asked, I assure people that Kathryn is able to communicate her needs and wants. It is nearly impossible to ignore Kathryn telling us something

that is important to her. Without spoken word, it is still possible to communicate. It is very possible to be a full participant in society and a contributing member of our community without being able to do certain things. Technology gives us even more avenues.

When Kathryn was very young we were fortunate to have access to Early Intervention. We know from our experience and from statements doctors and other professionals have made, that EI fundamentally changed Kathryn's trajectory. What we were told week two of her life was scary and shook us in a way that is hard to describe. No one could tell us what life would be like or what her prognosis was. No one would give us basic answers - and in some ways, I'm glad they didn't these many years later. What they did tell us is that the human brain is amazing and the more we did in the first months and years of her life to help "re-wire", the better her life would be. Thanks to our local chapter, The Arc of Montgomery, Berks, and Bucks Counties (now The Arc Alliance) and Overbrook School for the Blind along with our Supports Coordinators, Kathryn got PT, OT, Speech, educational services, and later some basic mobility training. It made all the difference in the world.

So, how do these stories come together? We had the opportunity for Kathryn to try some no-tech, low-tech, and technologybased solutions for communications over the last 14 years. The solution for Kathryn is a mix. However, on a few occasions we have had to fight very hard for Kathryn to get funding and access to the technology needed to allow her to communicate with a speech generating device. In one case, we were denied funding because the Medical Assistance program stated that Kathryn did not have the intellectual capability to benefit. We fought that hard and showed clearly that access to technology allowed her to communicate more easily with teachers, other students, and her family.

In the 21st century people with and intellectual developmental disabilities should have access to the technologies that can improve their ability to interact and participate in the world. This should not be the last step in a process of elimination, but rather one of the FIRST options considered. Technology is all around us. It is The Arc of Pennsylvania's position that technology tools should be much more available and considered as a solution to help bridge gaps and improve lives. As more technology becomes readily available and used, there will be market pressure

to invest in solutions for our constituents -- which is good for everyone. There will be more technology developed primarily for use by people with intellectual and developmental disabilities rather than relying on technology adapted from other fields.

The current budget discussions in Harrisburg include the first increase in direct service rates for Early Intervention in more than a decade. Many providers of these vital services are constantly struggling to recruit and retain the best talent and that is made very difficult by low wages and lack of investment in the training needed to ensure excellence. With the profound impact Early Intervention has on a person's life and future, I can't think of a more pressing reason for action this year and in the





future. Please take the time to write and call the Governor and your legislators to support this important budget priority.

Finally, this is my last opportunity to write the president's message for this newsletter. I'd like to take the opportunity to thank all of you -- our self-advocates and families: legislators: Governor Wolf and his administration; the many professionals who provide services to people with intellectual and developmental disabilities and their families: the multitude of volunteers across the Commonwealth; and to all of our chapters who represent The Arc in the local community. A special thank you to the fantastic, dedicated team of The Arc of Pennsylvania - those based in our Harrisburg office as well as those working in the field to help change the experience of children in schools and youth and adults transitioning to the next phases of their lives.

Over these two years we have seen a lot happen such as the tremendous growth of programs promoting competitive employment and big changes such as the retirement of Maureen Cronin and our new Executive Director, Sherri Landis, taking the lead. So much more is left to do. In June the Board's leadership team will change, but what will not change is the dedicated service and passion that my colleagues on the Board share. The executive committee and the Board at large have continued to work hard to advance our common goals and will continue to work for the rights of people with intellectual and developmental disabilities.

It has been a great honor and privilege to serve as president. Thank you for your support.

Michael J. Marsh President of the Board The Arc of Pennsylvania





Executive Director's Message Sherri Landis



For many of you, this is my first opportunity to reach out and introduce myself. My name is Sherri Landis and in January of this year, I became the Executive Director of The Arc of Pennsylvania. I am so excited to be part of this amazing organization! I always knew that The Arc of Pennsylvania was a leader in advocating for the rights of people with intellectual and developmental disabilities and their families in PA. Now, I know we are!

This association is managed by an exceptional Board of Directors. Your Board is committed, caring, and capable, and they have supported me in learning about the important work that needs to be done. The Arc staff is terrific. Each staff person has welcomed me and has not missed a beat in the transition from one Executive Director to another. Knowledgeable local chapter executives have offered their assistance and expertise. I am amazed at the commitment of our local chapters and local chapter volunteers and look forward to meeting more and more of you in the coming months. I have hit the ground running as the important work we do does not stop. It has been my pleasure to represent this organization with the Governor and with many local legislators and many governmental decision makers. This issue of the PA Message is about The Power of Technology. On a daily basis, I use technology. I use my "OK Google" alarm to get up every morning. I have three adult children in college, and we FaceTime one time a week to stay in touch. I use a computer to communicate with staff, legislators, and our local chapters. I use my phone to schedule an Uber to get me to various meetings. I use technology every day and many kinds to meet a variety of needs. Do we recognize that technology can be just as critical to people with intellectual and developmental disabilities? Many Pennsylvanians with intellectual and developmental disabilities encounter obstacles in their lives that can be overcome with technology, and while the benefits of technology are well known for use by people with disabilities, it remains an underutilized source of support.

At the March 9th meeting, your Board of Director's passed a Technology First position paper. A Technology First State embraces technology as a first source of support when addressing outcomes in service planning for people with intellectual and developmental disabilities. The Arc of Pennsylvania believes that both generic technology and specialized technology can be used to support inclusion in neighborhood schools, success at community integrated employment, increasing independence in the home and community, and aid in

safety and self-determination. Please check out the full position paper on our website at www.thearcpa.org and watch for more information to follow. We have much work to make Pennsylvania a Technology First State.

Please join us at this year's Advocacy & Policy Day on June 10th and June 11th, 2019. This year's workshops on the afternoon of June 11th, will showcase The Power of Technology: A Call to Action. Check out the agenda in this newsletter. You can register for the event at our website at www.thearcpa.org. Don't miss out on this opportunity to network with your legislators, meet decision makers, and learn about the many ways you can make a difference.

I look forward to working alongside you to make a difference. Please reach out to me if you have ideas for the work that we need to do. My email address is slandis@ thearcpa.org. I love new ideas!

Sincerely,

Sherri Landis

Achieve with us.







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TECHNOLOGY MAKES MY EVERYDAY LIFE POSSIBLE

By, Michael Anderson, Montgomery County

My name is Michael Anderson and I live in Montgomery County. The town I live in is called Merion Station. It is in the mainline right outside the city of Philadelphia, but still in Montgomery County.

I am employed by The Arc of Philadelphia as their Legislative Advocate. I love my job! My passion is making life better for all and especially for people with disabilities. Right now, I am working on a really big conference that we have planned during the month of May. It is called the Youth Leadership Conference and I am really excited about it.

In this job, I help people get a better life. Because I use technology, I often tell people about my personal experiences and ask them to consider if the use of technology would help them as well. When I share my personal experiences, others learn the important role that technology can play in building an EveryDay Life for people with disabilities.



Here is a picture of my van. This is an adaptive van. It has an automated folding ramp. Using my wheelchair, I enter the van. No one needs to lift me into the vehicle or position me in a car seat. I obtained my van via a loan

through the Pennsylvania Assistive Technology Foundation (PATF).

Because I have an accessible vehicle, I use the vehicle to travel in my community. I love being around people, and I am very active in my community. Using my wheelchair accessible van, I travel to work - (on time, I might add!) and to the National Constitution Center every Tuesday. I am a volunteer there. Using the van, I go to the local movie theater, travel to my family's home, and hang out with my friends.

I live in my own house. My home has automated doors so I can get in and out when I go places. Using smart home technology, I have full control over the lights, the television, and other appliances. Using my voice and an Amazon Echo, I turn on my TV and even change channels my favorite thing to watch is sports. I can play my favorite music and even call for a specific song. I love the music of the Dave Matthews Band. With just



my voice, I stop or start my fan, and turn on/off the lights.



My cell phone is also activated by my voice. I use my phone to call and talk to my family. I can also call for staff support when I need help to prepare my meals or when I want to get ready to go to bed.

And it is always important to keep Mom happy. So most importantly for me and for my mom and dad, this technology helps me stay safe. All I have to say is "Amazon Call Mom's Mobile" or reach out to staff for support.

The use of technology allows me to live an independent life, to work at a job I love, and to be part of my community. Can technology enhance your life?



Want to Stay Up To Date on What's Happening?

Get The Arc's Electronic Newsletter In your InBox 2 x per month Contact Amy Houser at ahouser@thearcpa.org to join the E-List for In Touch.



WATCH FOR MINITECH STORIES THROUGHOUT THIS ISSUE OF THE NEWSLETTER.

Author: Kim Singleton, MS, CCC-SLP, Director of TechOWL - Assistive Technology Programs, Institute on Disabilities @ Temple University. You can reach Kim at kim.singleton@temple.edu.

Do you think there might be a useful tool or technology out there? The first step is to decide what you wish was easier. Then ask what is making it hard. A tool that is right for one person might not be right for another person. It is important to explore different options with different features. Technology is changing at the speed of invention. It is possible that there will be new technology by the time you read this.



Amir says: "I wish it was easier to work. The problem is with my thinking. I can't remember my tasks when I am working at the grocery store. The problem happens with other people like my co-workers and boss." He and his support team could try a smart phone app called "CanPlan".

http://bit.ly/tech-canplan

REGISTER NOW!

www.arcpa.org
The Arc of Pennsylvania's 2019

Advocacy & Policy Conference
June 10-11, 2019

Harrisburg Hilton, Harrisburg, PA

June 10th, 2019

1:00 p.m. - The Arc of Pennsylvania Membership Meeting

1:30 p.m. - The Arc of Pennsylvania Board of Directors Meeting

3:30 p.m. - Pennsylvania Council of Executives of The Arc of Pennsylvania

4:00 p.m. - Mutual of America Networking Reception

June 11th, 2019

9:00 a.m. - Legislative Breakfast, State Capitol, East Wing Rotunda

10:30 a.m. - Disability Rally, Main Capitol Rotunda

11:30 - Lunch

12:30 - "The Power of TechnologyA Call to Action" Pop-upPresentations and Vendors

4:30 p.m. Event Ends





Your Voice Matters



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TECHOWL - TECHNOLOGY FOR OUR WHOLE LIVES

By Kim Singleton, April 2019

WHAT IS TechOWL?

TechOWL is a statewide group of programs and projects in Pennsylvania. TechOWL helps people with disabilities find tools and technology they need. TechOWL means Technology for Our Whole Lives. We help people explore technology and discover solutions. More information at https://TechOWLpa.org.

WHAT KINDS OF TOOLS?

TechOWL helps find tools and technology for school, work, and life in general. When a person wants to be more independent, technology can help. Solutions range from simple homemade items to complicated computers. We are here to help you navigate all the new gadgets and apps. There might be a solution that is brand-new. There might be an old tried-and-true fix. We are passionate about finding the right solution for you.

WHAT KINDS OF DISABILITIES?

TechOWL serves people in Pennsylvania with any disability. We help people with an intellectual disability. If moving or controlling is a challenge, there are many tools to explore. We also help people with sight or hearing challenges. There are new tools to help with learning and remembering. There are tools to help with organizing and completing. We also help people who support other people. If you are curious about remote monitoring, get in touch.

WHAT PROGRAMS AND PROJECTS?

TechOWL has a robust information center. You can call, email, text chat, or video chat to get in touch. We also have a lending library and offer demonstrations. We run a free phone program for people who can't use a regular telephone. Another program recycles used tools and technology. The iCanConnect program is for people with both vision loss and hearing loss. We provide micro grants to some people to help get what they need. TechOWL is busy.

WHO CAN USE TechOWL?

If you are a Pennsylvanian with a disability, you can use TechOWL. If you live in Pennsylvania and support a person with a disability, you can use TechOWL. We can demonstrate tools that you might want to explore. Any Pennsylvanian can borrow from our lending library. We might be able to provide a presentation to your group. Any person can ask us questions through a phone call, email, or text chat. Some of our projects and programs have specific requirements.

WHERE IS TechOWL?

We have nine regional centers across the Commonwealth of Pennsylvania. There is probably a regional resource center close to you. TechOWL creates partnerships with other organizations. Our resource centers are usually inside one of the partners. Our main office is in Philadelphia at Temple University. We also have partner locations in Allentown,



Camp Hill, Erie, Pittsburgh, Saint Mary's, Scranton, Washington, and Williamsport.

WHO PAYS FOR TechOWL?

Your tax dollars pay TechOWL. In most cases, our services are free to you. You already paid for these services when you paid your taxes. Did you know that every state has an Assistive Technology (AT) Act program? The AT Act programs get money from the federal government. TechOWL has that program for Pennsylvania. The federal government provides some money. The state government also provides some money. TechOWL also gets funding from other grants. If there is no other funding source, we can bill you directly, if you wish.

IS TechOWL PART OF THE INSTITUTE ON DISABILITIES?

Yes. TechOWL is part of the Institute on Disabilities (IOD). The IOD is part of Temple University. The IOD learns from, and works with, people with disabilities and their families. The IOD promotes self-determined lives. We want people to see disability as a natural part of the human experience.

WHAT ABOUT PIAT?

Remember PIAT? The AT Act Program in our state is Pennsylvania's Initiative on Assistive Technology. We call it "PIAT" (pee-aht) for short. PIAT is Pennsylvania's Assistive Technology (AT) Act Program. PIAT and the other assistive technology programs and projects create TechOWL - Technology for Our Whole Lives.

So, come visit us at https://TechOWLpa. org. We can help you get the tools and technology you need.

Author: Kim Singleton, MS, CCC-SLP, Director of TechOWL - Assistive Technology Programs, Institute on Disabilities @ Temple University. You can reach Kim at kim.singleton@temple.edu.



Joel says: "I wish it was easier to cook by myself. The problem is with my thinking. My family is afraid I will forget to turn off the stove and get hurt." He could try smart stove knobs.

http://bit.ly/tech-knob

Tools help people.

TechOWL finds tools and technology for people across Pennsylvania.



Institute on Disabilities at Temple University

	Lending Library see what items will work best for you	°°°	Affordable AT help in paying for what you need
	• Free Special Phones if you have difficulty hearing, talking, seeing, thinking or moving		• iCanConnectPA communication access if you have both hearing and vision loss
	Used Equipment Exchange buy, sell or donate		Testing and Recommendations to match your needs with tools and technology
505	Information and Assistance	Ch Ch	Training wide range of topics for your class or organization
	call, email or chat online	ररररर	your class or organization
	I	2,	Get Something Made if you can't find it at a store

VISIT OUR WEBSITE TO GET WHAT YOU NEED TechOWLpa.org

Pennsylvania's Initiative on Assistive Technology (PIAT) is part of TechOWL. tel **800-204-7428** email **ATinfo@temple.edu**



FUNDING INDEPENDENCE: ACCESSING THE ASSISTIVE TECHNOLOGY YOU WANT AND NEED

By Susie Daily, Outreach and Social Media Coordinator, Pennsylvania Assistive Technology Foundation

"With a child who does not use words to communicate, I felt we didn't have months," Lindsey said as she described the process of acquiring an iPad for her daughter Maci. Maci uses her iPad for communication. While she and her mom have their own ways of communicating without the iPad, this device makes communication with teachers, therapists, and friends easier—and Maci loves it! But, acquiring the iPad was more difficult than Lindsey bargained for. Countless phone calls with the insurance company, doctors' offices, and Durable Medical Equipment (DME) suppliers all seemed to lead her in circles. Even with a doctor's prescription, the iPad is considered a multipurpose device, so DME companies do not supply them. And while going directly through insurance was an option, the company indicated that the iPad would be denied, and fighting back would surely take months. That's when Maci's occupational therapist suggested she call Pennsylvania Assistive Technology Foundation (PATF). "The application was simple, and I got a reply so quickly!" Lindsey shared. "We received the check within a week to purchase the assistive technology."

New!



Download for free at: www.patf.us/FundingYourAT



Funding for AT is complex

The conversation around technology is often centered on new advancements and innovative applications, while consideration for how to pay for this technology remains an afterthought. In fact, one of the leading obstacles for many people in obtaining assistive technology (AT) is finding the money to pay for it. And, funding for AT is a complex subject. Your diagnosis, age, whether or not you are a student, where you live, whether or not you work, your financial situation, and your wants and needs all factor into determining what funding options are available to you.

In order to help you and your family navigate the complex web of funding resources available for AT, PATF recently published Funding Your Assistive Technology: A Guide to Funding Resources



in Pennsylvania. (Visit https://patf.us to download a free copy!) The Guide offers an overview of AT, gives considerations for choosing your AT, provides instructions on developing your funding strategy, describes how you can access AT through Home and Community-Based Waivers (and how you should go about appealing a denial), gives you a listing of private funding resources, and shares how you can save safely for AT through ABLE accounts and Special Needs Trusts.

Funding Resources

While every situation is different, the following list covers many available funding resources:

Home and Community-Based Services (HCBS) waivers fund a variety of in-home and community services and supports, including assistive technology for individuals with disabilities and older adults. Individuals must meet both functional and financial requirements to qualify for a waiver program. A range of AT devices and services may be covered, such as independent living technology or home and vehicle adaptations.

School districts provide AT to school-aged children as long as the device is educationally-related. This includes a variety of AT, like Maci's iPad in the story above, as well as devices such as hearing aids or AT that supports an individual's participation in extracurricular activities. For example, Tommy loves sports and was made the manager of his school's basketball team. Tommy has cerebral palsy and had a hard time projecting his voice loudly enough to be heard from the sidelines. The school district paid for a headset to amplify his voice during practice and games so the players could hear him.

Health insurance can also fund AT, but only if the need for the

continued on page 9

device can be linked to healthcare. Durable Medical Equipment (DME) is a type of AT funded by health insurance and includes devices like wheelchairs and hospital beds. However, health insurance can also pay for something like an iPad if the case can be made that the device is used to communicate about health. For instance, a child who does not use words to communicate might use their iPad to communicate where they hurt when they're not feeling well.

Private grants, such as ACHIEVA Family Trust, offer partial and full funding for AT. (Visit http://achievafamilytrust.org for more information.) Other organizations provide devices directly to beneficiaries. Variety Club in Western PA provides Rifton adaptive bikes, Kid Kart Mighty Lite adaptive strollers, and communication devices to children with disabilities. (Learn more at https://www.varietypittsburgh.org/).

The Office of Vocational Rehabilitation (OVR) can fund employment-related AT. Examples include generic technology devices needed to complete a job function, adaptations to a vehicle in order to commute to work, or hearing aids that facilitate communication with colleagues.

Pennsylvania Assistive Technology Foundation can help

Pennsylvania Assistive Technology Foundation (www.patf. us) helps Pennsylvanians of all ages, all income levels, and all disabilities and health conditions access the AT devices and services they want to improve the quality of their lives. PATF's programs include:

- Information and Assistance: Free information about AT, tips on how to access public/private resources, and referrals to recommended vendor companies are provided by staff.
- Two Financial Loan Programs:
 - Mini-Loans for amounts from \$100 to \$2000 at 0% interest, with no fees, and with monthly repayments starting at \$20. Because PATF reports all repayments to the three credit reporting agencies, a Mini-Loan is a great way to establish good credit, which is critically important when pursuing employment or housing.
 - Low-Interest Loans for amounts from \$2000 to \$60,000 at a fixed interest rate of 3.75%, no fees, and repayment terms based on the useful life of the device. If an applicant's overall credit does not meet conventional lending standards, PATF may guarantee a low-interest loan up to \$35,000.
- Financial Education: PATF staff provides one-on-one coaching and counseling to applicants as well as group trainings to the greater disability community to increase understanding of money matters, and thus increase independence.

PATF incorporates consumer-direction and consumer-control into its programs, which means borrowers can purchase the devices of their choosing from the vendors of their choosing. It also means PATF supports the purchase of generic, off-the-shelf technology to increase independence, autonomy, and safety. This technology, such as the Amazon Echo, is often easier to find and less expensive than specialized equipment, and the training and repair services are also more readily available.

The right assistive technology can provide independence and autonomy, improve quality of life, and make it possible to go to work, live in your own home, and participate in your community. There are many ways to fund your AT, it's only a matter of finding the right solution for you.

About the Pennsylvania Assistive Technology Foundation

Pennsylvania Assistive Technology Foundation (PATF), founded in 1998, provides education and financing opportunities and advocates for people with disabilities and older Pennsylvanians, helping them to acquire assistive technology devices and services that improve the quality of their lives. It is headquartered in King of Prussia, PA and uses a network of Funding Assistance Coordinators across the state to assist prospective borrowers. The organization's website is www. patf.us. Contact them at (888) 744-1938, or patf@patf.us. PATF is also on Facebook and Twitter.

Inclusive. Dedicated. Determined.



STATE PROGRAM EXPANDS ACCESS TO A.T. AND REMOTE SUPPORTS

By: Jeremy Yale, Director, Bureau of Policy and Quality Management, Office of Developmental Programs

The mission of the Office of Developmental Programs (ODP) is to support Pennsylvanians with developmental disabilities to achieve greater independence, choice, and opportunity in their lives. By introducing new and innovative technology in a person's life and incorporating it into meaningful planning; more people will achieve greater independence and choice in their home and communities. For this reason, ODP is developing a multi-pronged approach to expand access to assistive technology and remote supports. This plan involves all

stakeholders and will be an important cornerstone of the Office's policy platform for 2019-2020.

What AT is covered?

Assistive technology includes safety sensors, devices that remind individuals of appointments or medication times, and software/applications on computers and smartphones. Remote supports combine staffing resources and electronic devices to create real-time, two-way communication between direct service professionals and individuals living in an apartment or their home. Home-based sensors, cameras, and other technologies allow the functionally to provide care from a remote location, supporting a person's need for greater independence while reducing costs and allowing providers to utilize staffing resources in other settings. Both assistive technology and remote support services are available through ODPs four home and community-based waiver programs.



Technology =
Greater
Independence
and Choice

Technology Strategy In Pennsylvania

In 2019, ODP will be hosting two statewide Technology Innovation Conferences, which will feature Pennsylvania providers that are incorporating technology to support individuals. The conference is designed to be a starting point, in which participants will explore possibilities and have access to "hands on" technology and vendors.

Another initiative, the Office of Developmental Programs is forming a

Technology Workgroup to inform decision-making, identify statewide innovation projects, and support the planning efforts of the Statewide Technology Innovation Conference. The workgroup will help to identify local champions, which will lead efforts within their communities to develop and expand access to assistive technology and remote supports. Furthermore, the workgroup will serve as a forum to review service definitions and recommend improvements that make technology more accessible to individuals, families, and support teams.

ODP has recently joined The National Association of State Directors of Developmental Disability Services (NASDDDS) Technology Workgroup, which provides member states the opportunity to discuss innovation and technical guidance to advance. Additionally, ODP has been in communication with Ohio, which by executive order is a "Technology First" state. This model creates additional opportunities and resources for individuals, families, and support teams to explore the use of technology to promote independence.

Finally, ODP is working to enhance the relationship with Pennsylvania-based Technology Vendors/Contractors. This is intended to create additional capacity and bring new ideas to the planning process. In other states, technology vendors have the experience to work with teams to inform the many possibilities and point out some of the limitations of assistive technology.

With many emerging uses of technology to support independence, the Office of Developmental Programs is incredibly excited to be part of this movement and anticipates future collaboration with The Arc of Pennsylvania and its affiliates.



USING OFFICE OF DEVELOPMENTAL PROGRAM WAIVERS TO FUND TECHNOLOGY



What Technology can be funded? An item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve a participant's functioning or increase a participant's ability to exercise choice and control.

Electronic devices that are separate from independent living technology are included under Assistive Technology to meet a communication or prompting need. Examples of electronic devices include tablets, computers, and electronic communication aids. Electronic devices include tablets such as iPads and

Samsung Galaxy tablets. Hearing aids for adults (participants age 21 or older) are covered as Assistive Technology.

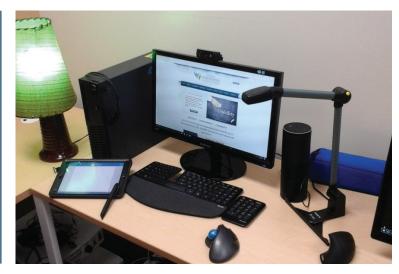
Independent living technology is included for participants age 16 and older. The purpose of independent living technology is to assist participants in obtaining and/or maintaining their independence and safety within their home and community and decrease their need for assistance from others. Independent living technology involves the use of remote monitoring services and/or equipment in conjunction with additional technological support and services.

Examples of equipment and services covered as independent living technology include medication dispensers, door sensors, window sensors, stove sensors, water sensors, pressure pads, GPS Tracking Watches, panic pendants, and the remote monitoring equipment necessary to operate the independent living technology. This service includes the costs for delivery, installation, monthly adiustments. testing. monitoring, maintenance, and repairs to the independent living technology equipment.

For more information about using Waiver funding (Person Family Directed Supports, Community Living, or the Consolidated Waivers) for Assistive Technology, please contact your Support Coordinator.

Source: Office of Developmental Programs Bulletin 00-17-03, Commonwealth of Pennsylvania Department of Human Services, Office of Developmental Programs Individual Support Plan (ISP) Manual for Individuals Receiving Targeted Support Management, Base Funded Services, Consolidated or P/FDS Waiver Services or Who Reside in an ICF/ID.







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Technology First Position Paper

Approved by The Arc of Pennsylvania Board of Directors, March 9, 2019

ISSUE: Establish Pennsylvania as a Technology First State

BACKGROUND: A Technology First State embraces technology as a first source of support when addressing outcomes in service planning for people with intellectual and developmental disabilities.

The use of technology and the types of technology being used is increasing. On a daily basis, we rely on technology for information, connections to others, and assistance in our daily lives. More technology is under development and will continue to impact our lives in different ways. In fact, technology is being implemented in almost every aspect of our lives and business functions. "Technology is unavoidable and mandatory to function as a citizen of today's world. Interacting with technology should no longer be considered optional." (Source: Innovations in Supporting Families, Issue Brief: Technology & Supporting Families, Community of Practice Framework for Systems Series)

The Arc of Pennsylvania promotes the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes. An increasing number of people, using their person centered planning resources, are using generic and specialized technology for learning, inclusion, safety, self-determination, and increasing their independence as they live in their community. Many Pennsylvanians with intellectual and developmental disabilities encounter obstacles in their lives that can be overcome with technology and while the benefits of technology are well known for use by people with disabilities, it remains an underutilized source of support.

The focus on technology as a first consideration in person centered planning is consistent with The Office of Developmental Programs Everyday Lives document and efforts to embed The Life Course Framework into how we do business here in Pennsylvania. Charting the LifeCourse is a framework that was developed to help individuals and families of all abilities and at any stage of life, develop a vision for a meaningful life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live.

POSITION

The Arc of Pennsylvania believes that technology can be used to support and enhance an individual's life.

The Arc of Pennsylvania believes that both generic technology and specialized technology can be used to support inclusion in neighborhood schools, success at community integrated employment, increasing independence in the home and community, and aid in safety and selfdetermination.

In seeking to become a Technology First state, Pennsylvania follows the commonwealth of Ohio in establishing a Technology First Initiative to expand the use of technology for individuals with intellectual and developmental disabilities. continued on page 13

"Technology, loosely defined, is the creation and use of devices that allow us to interrelate with society and the environment. They may be as simple as a light switch or as complicated as computer networks that fill entire rooms." (1) There is a rapidly expanding landscape of technology to support Pennsylvanians in connecting with others, controlling their living space, securing safety, and increasing quality of life. Pennsylvanians can play a key role in shaping how these emerging technologies impact the lives of people with intellectual and developmental disabilities and their families.

Technology First does not mean that people need to replace or revise their emphasis on person centered planning and formal disability services. Technology First embraces person-centeredness. Technology First requires the integration of technology into a person's home, work, and community. While a technology first approach does not replace staff, it may impact where staff are allocated and how long staff are needed for certain kinds of assistance.

The Arc of Pennsylvania's position includes:

 The Arc of Pennsylvania seeks an Executive Order or Legislative Action that establishes Pennsylvania as a Technology First State. A Technology First state embraces technology as a first source of support when addressing outcomes in service planning for people with intellectual and developmental disabilities.

- All people with disabilities should be afforded the opportunity to enhance their lives through the use of technology. To that end, people with intellectual and developmental disabilities, their families, and planning teams have access to information about the varied types and uses of technology needs.
- 3. Technology that is intended to address an individual's assessed needs shall be prioritized when considering services and support needs.
- 4. The commonwealth of Pennsylvania should establish a Technology First Council to advise departments under the Governor's jurisdiction, about the ways to expand the use of technology for Pennsylvanians with intellectual and developmental disabilities. In addition, the council should develop strategies to expand the use and understanding, as well as funding opportunities to increase access to technology.

Information Sources:

- Everyday Lives, https://www.myodp.org/mod/page/view. php?id=7775
- Charting the Life Course, http://supportstofamilies.org/ wp-content/uploads/CoP-Innovations-Technology-Issues-Brief.pdf

Approved by The Arc of Pennsylvania Board of Directors, March 9, 2019.

LEARN MORE, DO MORE

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

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

A CALL TO ACTION

Joe Mancini, Executive Director, The Arc of Philadelphia

School has always come with a set of challenges for my daughter, Lillian. Lillian was diagnosed with Dyspraxia, a developmental disorder that affects her coordination. She has a visual impairment - legally blind in her left eye. After her diagnosis at age 5, we discovered the areas in which she struggled, and our family began working with the school to have a 504 Plan implemented to aide in her day-to-day learning and activities. Headphones addressed her sensory issues. Standing desks alleviated her muscle tension and low muscle tone. Preferential seating (sitting up front in the classroom) accommodated her visual impairment.



Middle School Challenges - The Locker

Fourth grade brought its own unique set of challenges as she transitioned to the Intermediate School. She was now with older students, crowded hallways, and our current arch nemesis... lockers. While all students struggle with opening their combination lockers, Lillian had a particularly difficult

time. The incoming students place pencils in their locker handles to hold the doors open until each learned how to use the combination locks. One by one, pencils began disappearing from the students' lockers until only Lillian's remained.

Every night we practiced at home as Lillian's frustration snowballed. Her limited motor skills and inability to recognize small numbers on the combination lock began to make this task seem insurmountable. Lillian was singled out by the bright yellow, number two sign of disability (the pencil) she kept in her locker door. It did not take long for other students to take note and begin teasing Lillian at her locker. Lillian began to dread her morning routine, and eventually school all together. Every morning was a reminder of how she was different, and it began to take its toll. We discovered a simple fix, a lock that opens with a thumb print. This minor piece of assistive technology could solve all of her fourth grade woes. And the cost was between \$20 - \$60.



Technology does not have to be costly

This is what people fail to realize. Assistive technology does not have to be costly. While there are futuristic devices we see on the internet, or Elon Musk's next million dollar innovation on the news, they should not overshadow the accessibility of the technology now available to all people in 2019.

Increased advocacy on technology use

The Arc of Philadelphia is making the promotion and integration of Assistive Technology in daily living a focus of our work. We are working with the Coleman Institute on several initiatives that would make the benefits of assistive technology widely known throughout the community and with our legislators.

Councilman Green's office drafted a resolution that declares the importance of assistive technology throughout the City of Philadelphia, and we are a part of the team that is attempting to make Pennsylvania an Assistive Technology First State. Together, lawmakers and The Arc of PA are working towards legislation that would focus on assistive technology as a source

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of support and considered in every individual's support plan. In addition, The Arc of Philadelphia is working with Comcast to become a tech coaching center where we will begin providing assessments and training on what assistive technology (AT) is available, how to use this AT properly, and where to access the funding We are highlighting the need for this technology at every event, conference, and meeting we have to spread the awareness of how AT can benefit individual's everyday lives.

Our Call To Action

To every person, organization, and company that supports a population in need for assistive technology, THIS IS YOUR CALL TO ACTION. As a society, we are afraid of change, and we so often ignore the benefits of something new while reverting to past-norms. This mindset and approach are no longer acceptable. As leaders and servicers for these communities, you have the opportunity to be the agents of change that are so desperately needed to integrate assistive technology into the lives of the people that need it most.

When implemented correctly, technology reduces personal care cost, limits the amount of extraneous supports needed,

and allows people to truly take the steps toward independent living. Share the work you are doing to support this initiative. If you are not currently focusing your work in promoting AT for the populations you serve, redirect your agenda to do so because you are the link the AT field needs going forward. The future truly is now.

It could have been different for Lillian

Lillian never received her thumb print combination lock. The school was less than supportive of allowing Lillian to utilize this solution she desperately needed. One year later, Lillian was able to open her locker; but, that was a year of frustration and feeling outcasted because of her disability. Imagine how her experiences at school could have been different if everyone was a little more aware and supportive of the benefits of assistive technology.

Joe Mancini is the Executive Director of The Arc of Philadelphia. He is also the President of the Pennsylvania Council of Executives for The Arc of Pennsylvania. He can be reached at: jmancini@arcphiladelphia.org.





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The Power of Technology: A Call to Action What's Available? What's Emerging? How to Get it!

June 11th, 2019 - 12:00 to 4:30 p.m. Harrisburg Hilton, Harrisburg, PA

Speakers from: SunKirb Ideas, LLC, Comcast, Technology Users, Office of Vocational Rehabilitation (OVR), Office of Developmental Programs (ODP), Pennsylvania Assistive Technology Foundation (PATF), TechOWL/Temple University.

Vendors: The Arc of Susquehanna, J.A. Kolva, TechOWL, Pattan, ODP, OVR, PA ABLE, Hunter Douglas, Inclusive TLC, Vision Resources of Central Pennsylvania, PATF and more.

Visit the ON SITE Technology Room!

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