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**HOUSE OF REPRESENTATIVES**  
COMMONWEALTH *of* PENNSYLVANIA

*House Democratic Policy Committee Hearing*

The Interaction of the Disabled Community with Technological Innovation.

Thursday, September 22, 2022 | 3:00 p.m. – 4:30 p.m.

Representative Joe Hohenstein

**PARTICIPANTS**

Tom Carasiti, Community Advisor  
*Vision for Equality*

Kim Singleton, Senior Director of Assistive Technology Programs  
*TechOWL at Temple University*

Shea Tanis, Associate Research Professor  
*Kansas University Center on Developmental Disabilities*

Neil McDevitt, Executive Director  
*Deaf-Hearing Communication Centre*

Debbie Robinson, Advocate, Executive Director  
*Speaking for Ourselves*

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## 2022 Disability Summit: Enabling Technology

Tom Carasiti

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732-533-3971

Eileen MacDonald, Executive Director, Delaware County Advocacy and Resource Organization

[emacdonald@delcoadvocacy.org](mailto:emacdonald@delcoadvocacy.org)

610-544-6600

My name is Tom Carasiti. I live in Delaware County and I'm a parent of a 31 year old son with Intellectual Disability and Autism. I advocate with Vision for Equality, and I participate in two of their programs, the Pennsylvania Waiting List (PAWL), which I think most of you are familiar with, and Voices Rising for Justice (VRfJ), which is a collaborative effort, led by Vision, of several advocacy groups and providers with the purpose of reducing/eliminating the neglect and abuse of developmentally disabled individuals.

Thank you for this opportunity to speak with you.

Voices Rising for Justice began its effort in Spring of 2021 with a letter to Governor Wolf stating the seriousness of neglect and abuse among the developmentally disabled. We included suggestions to improve or eradicate the issue.

For clarification, when I use the term 'neglect and abuse', I'm referring to many levels. It can be in the form of being the victim of derisive comments, bullying and name-calling, ignoring needs, abandonment, and up to the levels of repeated emotional, physical, or sexual abuse.

I have included in my written testimony to the committee, the 2021 letter to the Governor and a two page fact sheet that summarizes the letter. In brief, government statistics demonstrate, this population is many times more likely to be neglected or abused than their neuro-typical peers. Additionally, because many in this population have poor or no language skills, most incidents are unknown, go unreported, and even when reported, there's little chance of prosecution when criminality occurs. Facts are: many times, it is perpetrated by someone the victim knows.

Page two of the fact sheet outlines several areas, if addressed, we think will help. Consistent with today's Disability Summit theme 'Enabling Technology', I'll speak to the role technology could provide.

The Office of Developmental Programs (ODP) is pursuing technology to promote independence with assistive technology and/or technology for remote support, something that can help reduce in-person support costs and address the labor shortage of DSPs. We support that effort, but we would like an equal effort, which is not happening, to pursue technology that can help reduce or eliminate neglect and abuse. We want ODP, OLTL, and any PA agency that cares for

our vulnerable population to partner with tech vendors to develop, not just enabling technology, but better products to identify and root out abuse.

At the very least, cameras for video and sound, should be offered in any setting ODP or OLTL is delivering a service. Cameras can be a deterrent, or if incidents occur, provide the evidence needed for corrective action or successful prosecution of criminality. The Centers for Medicare and Medicaid Services (CMS) and ODP permit cameras but, they are rarely used. Every individual in our system should not just have the choice of technology for independent living but be reminded and offered choices of technology that will keep them safe from abuse.

And cameras are not the end all. In fact, cameras alone have their limitations. For one, currently they must be reviewed or monitored. Recently, it was learned physical and sexual abuse was ongoing for years in a Philadelphia facility that had cameras installed...no one was monitoring or reviewing the video. Monitoring requires additional personnel on the part of the Providers, personnel they don't have or can afford. Plus, cameras can't and shouldn't be everywhere in the home. Individuals we serve have the right to their privacy.

One technology that exists, currently expanding in the digital world, is artificial intelligence (AI). AI is in chips that drive cars, chips that interpret medical readouts, and bots that read our email or cloud storage for marketers. We are beginning to see AI coupled with cameras; in doing so, it may supersede the need for monitoring personnel. For one, in-home cameras with AI are now available where the people are on video as stick figures, offering more privacy for the individuals and caregivers. Available now, are cameras with AI that learn and interpret daily routines to alert the care team of critical anomalies in the routine, such as not taking meds or a fall. They are mostly marketed for seniors with varying degrees of dementia. I would like to see AI technology in a camera or other device that will determine when abuse is taking place. AI could learn and then interpret language, voice tones, situations, or anomalies that indicate someone is being neglected, bullied, disparaged, or worse, the AI determines physical abuse is taking place. When any occurs, immediate alert types can go out to the wider circle of support and respond in kind. I'm not an AI scientist, but the little I've read, I don't think this is outside the realm of possibility. AI is already being trusted to make medical diagnoses with real time alerts when needed. I have a relative with Type 1 diabetes, he has a small device that monitors his blood glucose 24/7 and sends alerts to his wife and daughters if he's nearing dangerous high or low levels. What about a device that can detect dangerous anxiety levels or vocal cues of a developmentally disabled person indicative of high levels of fear or harm?

There's a device on the market today that provides location information to a backup care team. It can be worn on the person in the home or community and provide real-time location, like some phone apps parents use to track their kids. But this device will also provide alerts to a designated care team of up to two people if someone's location is outside expectations. It provides the care team an option to immediately audio one way and listen to what's happening or have a two way conversation without the individual having to push a button. My question to the device developers, are there plans to upgrade the device to be always listening or viewing,

without transmitting, and using Artificial Intelligence, decide when something is amiss and needs an alert to care team and only then upload video or audio?

Yes, what I've just described is Big Brother type stuff. It's not for everyone. It must match the individual's level of need and personal choice by them or their care-team. However, there are many developmentally disabled who require a Big Brother (aka caregiver) to live a life in home and community that you and I take for granted. But statistics show, not everyone providing care, like in all professions, have good intentions. Because of the severity of my son's disability and others like him, we parents have an overarching, over aching, emotional weight we feel about who will watch over him the way we do when we're gone. How can we go in peace, not knowing if the system will keep him or her safe and happy. It's a pervasive dark cloud overhead that only parents like us share.

Today's conference theme is technology. Technology is just one of several measures we can take to reduce/eliminate neglect and abuse. Voices Rising for Justice is advocating for all the measures outlined in your attached Governor's letter and fact sheet. We urge you to partner with us and support policy for all our recommendations. DHS, ODP, OLTL are looking at technology for independent living, such as making sure stoves are turned off, water is not left running, individuals don't wander off the premises, etc. We want you to encourage ODP and OLTL with policy and funding that supports research, development, and use of devices that are specific to keeping our vulnerable citizens free from neglect and abuse.

Again, thank you for your time.

Attachments: April 2021 Letter to Governor Wolf to Address the Abuse of PA Disabled Citizens

Voices Rising for Justice – Abuse and Neglect Fact Sheet



April 24, 2021

Governor Tom Wolf  
Office of the Governor  
508 Main Capitol Building  
Harrisburg, PA 17120

**RE: Immediate Need for Addressing Abuse of PA Citizens with Disabilities. They cannot wait any longer.**

Dear Governor Wolf,

As you are aware through our many partnerships, for over 25 years Vision for Equality has worked tirelessly towards our mission of assisting and empowering people with disabilities and their families to seek quality and satisfaction in their lives as well as equal access to support and services. Dedicating ourselves and believing in an individual- and family-centered outlook in the Intellectual Disability Community has allowed us to remain on the forefront of the disability rights movement.

While we have addressed a variety of pressing issues, none have been more in need of change than addressing the **crisis of abuse and neglect of individuals with disabilities**. The most recent article detailing the ongoing [Devereux Abuse Scandal](#) brings up the fact, that there remains **no meaningful infrastructure in PA to protect its most vulnerable citizens**. Even though [State Representative Katie Muth called for formal investigation](#), the impact of Devereux's egregious abuse and neglect hasn't seemed to move other policy makers to make the changes needed to ensure that people with disabilities are protected once and for all. Devereux is in a long line of our state's failure to protect those with disabilities, particularly for those who lack the ability to self-report or who are afraid to do so.

National statistics confirm that individuals with disabilities are **seven times** more likely to be a victim of sexual assault, as well as having increased incidents of neglect and abuse. These citizens continue to be left behind in discussions about combating abuse and victim's rights. The 2018 NPR series, "[Abused and Afraid](#)," which featured reports from Joseph Shapiro, revealed how this is truly a hidden epidemic. While this report angered and moved advocates and lawmakers alike to address the crisis; in January 2020, the Office of Inspector General report found **PA has continued to fail at addressing abuse and neglect with their mishandling of more than 10,000 incidents!** The brief and full report can be found [here](#). This is unacceptable, we need actionable steps

Vision for Equality fought for nearly a decade and was instrumental in seeing the PA [2010 Adult Protective Services Act](#) put in place to protect adults aged 18-59 with disabilities. Now, a full decade later, no meaningful regulations have been put in place to give this Act the leverage needed to carry out those protections. In 2019, as Governor, you enacted an [Executive Order](#) to protect vulnerable populations from abuse and neglect and established the Office of Advocacy and Reform and the Council on Reform. While we applaud your intention; **adults with disabilities were provided the least amount of effort and resources in the Council's outlined objectives, membership, and goals**. Naming a council is simply not enough, we need **action**, and we need it now. We did provide the Council our public comment and suggestions in December of 2019 but have not heard from the Council or seen any efforts enacted since that time.

We believe that the Pennsylvania House Human Services and Senate Health and Human Services Committees have an obligation to ensure that regulatory legislation, designed to protect vulnerable populations, is finally put in place to seal these protections. We strongly suggest that the work of these committees should include legislation that targets the use of monitored security cameras in homes and residential settings to provide a "key witness" to abuse. Many of the supported individuals have severe cognitive and language challenges and are often falsely considered

unreliable or incapable witnesses to an incident of abuse or neglect which is critical in establishing an offense or a crime. For some a camera maybe **the only witness** and is essential in seeking criminality, ridding the system of an abuser. In many instances it is the only reliable source to protect the person.

**Provider accountability around abuse and neglect must be additionally prioritized in these efforts.** Providers currently continue to be able to self-report and investigate incidents under the [6400 Regulations](#) much to the disapproval of self-advocates and families. Progress is unattainable when the investigating agency is itself. We are protecting a population, many with extremely limited communication skills, with no independent oversight. While the current regulations *do allow* for monitored security cameras; many providers fail to even explore this. Their resistance is even after a handful of providers have successfully begun using them in residential settings and provider-owned vehicles. Providers continually claim that monitoring security cameras violate staff member's privacy and are cost prohibitive. It does not take much to see how ineffective our current PA regulations are to protect individuals when the providers continue to be able to have choice and control around security camera utilization. [CMS's Final Rule](#) does support the use of monitored security cameras that are utilized in a person-centered approach, so we must follow the lead of other states like [New Jersey who are working to enact legislation that would require the use of monitored security cameras to address neglect, abuse and incidents](#) over simply allowing the choice of utilizing security cameras up to providers.

We recognize that there are many hurdles, barriers, and resistance of providers to having monitored security cameras in residential settings and additional privacy considerations for individuals as well. We believe the benefits are worth fighting for to end abuse and neglect. We are not suggesting that they be placed in ways that limit privacy or dignity but for everyday citizens in PA the [law](#) is clear on their right to have home security cameras. What is not clear is how that translates to a provider setting for those with disabilities, particularly those with communication differences or incapacities. For those most vulnerable, security cameras, monitored and recorded, are a key witness. **Yet how many more stories must we hear like [Devereux](#), [Blossom](#) or [McGuire](#) before we create meaningful solutions?** Monitored security cameras may have prevented it all together or in the very least ended the decades long abuse much sooner. [The debate over security cameras in provider settings has been going on for over a decade.](#) We have done enough talking, it is time for action.

We recognize there are many areas of need in addressing the complex issue of abuse and neglect. Yet the way we can elicit meaningful change is through micro-progression that targets the same outcome: **to end abuse and neglect for vulnerable people once and for all.** One of those ways is to require the use of security cameras by providers. We have long supported other actions, including the creation of an Abuse Registry in PA of caregivers that prevents the hiring of those that have founded cases of abuse and restrict the providers ability in hiring known offenders that put residents at further risk. Yet year after year, legislators in PA fail to join the more than 26 other states that have registries addressing these concerns and hiring practices. We must agree on the need for multiple prong approaches and stop seeking a "one size fits all" solution over creating any solution at all and just returning back to business as usual; that is until the next "Devereux" story.

Vision for Equality would appreciate the opportunity to partner with you, the Department of Human Services, PA Senators and PA House of Representatives to create sustainable solutions immediately. One of which we believe is **requiring cameras to be used with consent by the individual(s) and their families in residential settings.** We recommend consideration of the following 6 prong approach:

- Require mandatory use of technology, currently video monitoring with audio and night vision, in residential settings to greatly reduce incidents of abuse and neglect. Other technology that can achieve the same result should be considered as technology continues to evolve. The rights of individuals with intellectual and



# Vision for Equality

Serving People with Disabilities and Their Families

developmental disabilities, including the right to privacy, should be preserved to the greatest extent practical. Just like any other citizen, the individual and their family have a right to choose and may consent to the limitation of the individual's privacy, by knowingly agreeing to video monitoring. While the current regulations *do allow* for security cameras; many individuals living in residential settings are denied the choice and control to use them in their homes that are supported by providers.

- Emphasize the need to comply with the CMS HCBS Final Rule which includes accommodations and practices that include the person and their family at the center of every consideration and decision that may or does affect them. We support self-direction in this initiative which includes the people who act as supportive decision makers and extends the context to all places and providers. This includes the individual and their family can select and deselect staff at any time for any reason without fear of reprisal or loss of services. Commitment, not just compliance, with on-going collaboration and coproduction of services and supports is necessary to ensure our mutual goals.
- Ensure everyone has access and support to own their communication. This is especially relevant for those who do not communicate using their voice or language comprehension is challenging. Mandating this, as we do for other aspects of a person's support is critical and should not be left to the provider to assess and approve.
- Develop and maintain an Abuse Registry of caregivers who have founded cases of abuse, neglect, and/or exploitation, similar to the law passed in [Massachusetts](#) in February 2020 with unanimous House, Senate, and Administration support.
- Increase provider accountability and transparency. Providers currently self-report and investigate incidents under the [6400 Regulations](#), much to the disapproval of self-advocates and families. **Investigations should be independent and conflict free.**
- Enact regulations, for the decade old, PA [2010 Adult Protective Services Act. This act](#), put in place to protect adults aged 18-59 with disabilities, needs governing regulations to carry out its protections.

As Governor, we hope you will join us in our efforts to hold legislators, DHS, and PA's APS accountable and work together to create and implement the change needed to end abuse and neglect for people with disabilities in PA. While we are aware that the planned March 2020 hearing in the House Human Services committee was postponed by the pandemic, it is beyond time to hold hearings on this issue. We want your Administration's support when we again ask that public hearings are held in the House and Senate **immediately** to address abuse and neglect and the use of security cameras in residential settings and vehicles. We believe that individuals and their families should have the opportunity to be informed of all system changes and be the ones who participate in **all** policy reformation that will impact their lives. With Administration support, we will ensure that they are informed of the hearings and our efforts to create true and lasting change as well.

There is a saying in the disability community among self-advocates and their families, **"Nothing about ME, without ME."** All efforts to support and protect individuals with disabilities must include their voices at policymaker's tables.

If you have any questions, please feel free to contact us. We would welcome a meeting virtually to discuss next steps on how cameras and a registry can be a meaningful part of our joint efforts in Pennsylvania to end abuse and neglect today. Thank you for your time and dedication to this important issue. The work of justice and advocacy is never done; we must be diligent daily to ensure that we tirelessly seek equitable and just communities for ALL people.



# Vision for Equality

Serving People with Disabilities and Their Families

Security cameras and monitoring do not just reduce incidents; they save lives. We believe ensuring people's safety and well-being is the highest priority of services provided to our loved ones.

Sincerely,

*Audrey Coccia*      *Maureen A. Devaney*

Audrey Coccia

Maureen Devaney

Co-Executive Directors

CC: Robert P. Casey Jr., US Senate  
Theresa Miller, Secretary, Department of Human Services  
Meg Snead, Acting Secretary, Department of Human Services  
Michele Brooks, Majority Chair, Senate Health and Human Services Committee  
Bob Mensch, Vice Chair, Senate Health and Human Services Committee  
Art Haywood, Minority Chair, Senate Health and Human Services Committee  
Frank Farry, Majority Chair, House Human Services Committee  
Angel Cruz, Minority Chair, House Human Services Committee  
PA Senate Health and Human Services Committee Members  
PA House Human Services Committee Members  
Dan Miller, Chair, Democratic Caucus  
Kristin Ahrens, Deputy Secretary, Office of Developmental Programs  
Michael Gamel-McCormick, Disability Policy Director, Special Committee on Aging, for Senator Bob Casey  
Drew Wilburne, Director of Intergovernmental Affairs, Department of Human Services  
Denise Getgen, Director of Protective Services, PA  
Kathleen Buckley, Director of the Office of Victims Service, PA  
John Delaney Jr., Esq., Chair, Victims Services Advisory Council

**The Following Organizations have additionally signed on to this letter in agreement:**

Eileen A. MacDonald, Executive Director, [Delaware County Advocacy and Resource Organization](#)

Matthew Seeley, Esquire, Executive Director, [Pennsylvania Statewide Independent Living Council \(PA SILC\)](#)

Donna Bouclier, Chief Executive Officer, [Terrapin House](#)

Marian Frattarola-Saulino, Founder and Executive Director, [Values Into Action](#)

Debbie Robinson, Executive Director, **Speaking for Ourselves**

Sheila Stasko, Director, [PA Waiting List Campaign](#)

Meghann Luczkowski, Program Manager, [PA Families Need Nurses Now](#)

Joan Nelson and Ramona Griffins, Managers, [Envision New Possibilities](#)

Barbara Nattile, Manager, [Philadelphia Parent Support Groups](#)



Tom Carasiti, Board Chair, **GDC Lifespan**

**Resources to consider related to ending abuse and neglect for PA vulnerable populations:**

**Article on Devereux:** <https://www.inquirer.com/news/inq/devereux-advanced-behavioral-health-abuse-children-pennsylvania-20200811.html>

**Allegheny County caretaker charged with attacking man with autism and intellectual disabilities:**

<https://pittsburgh.cbslocal.com/2021/01/12/allegheny-county-caretaker-charged-with-attacking-man-with-autism-and-intellectual-disabilities/>

**PA Provider McGuire wrongful death case:**

<https://www.timesonline.com/news/20191122/abuse-wrongful-death-suits-filed-against-mcguire-memorial-former-employees>

<https://www.ellwoodcityledger.com/news/20200227/former-mcguire-memorial-employee-pleads-guilty-to-dozens-of-charges/1>

**PA Provider Blossom wrongful death, poor handling of case and closure of provider:**

<https://www.inquirer.com/philly/business/death-disability-blossom-philadelphia-intellectual-20180425.html>

<https://www.inquirer.com/philly/business/blossom-philadelphia-closing-at-end-of-the-year-20180912.html>

**NJ proposes bill to require providers to have cameras in group home settings:**

<https://legiscan.com/NJ/bill/A4013/2020>

**NPR Abused and Afraid Series:**

<https://www.npr.org/series/575502633/abused-and-betrayed>

**PA 2020 OIG Report Summary (over 10,000 incidents of abuse and neglect were not reported or underreported):**

<https://www.oig.hhs.gov/oas/reports/region3/31700202.asp>

**Adult Protective Services and link to Act 70 (no regulations have been passed to support this bill, a decade later):**

<https://www.dhs.pa.gov/about/Fraud-And-Abuse/Pages/Adult-Protective-Services.aspx>

**Executive Order to Protect Vulnerable Populations:**

<https://www.governor.pa.gov/newsroom/gov-wolf-acts-to-reform-services-and-systems-to-protect-and-advocate-for-vulnerable-pennsylvanians/>

**PA Regulations Current Updates around HCBS related to Regulations 6100-6500 (Providers self-report and investigate incidents of abuse and neglect):**

<http://www.pacodeandbulletin.gov/Display/pabull?file=/secure/pabulletin/data/vol49/49-40/1509.html>



## Abuse of Individuals with Intellectual Disabilities (ID) and Autism (ASD)

### The Facts:

- In a study of 8-17-year-olds, researchers found that children with ASD were more than three times as likely to be bullied than as their peers. (Twyman et al., 2010)
- US Justice Department data between 2011 – 2015: individuals with a cognitive disability were almost 6 times as likely to be victims of violent victimization (physical assault, robbery, or sexual assault) than people without disabilities.
- US Justice Department data show that people with ID are the victims of sexual assaults at rates more than seven times those for people without disabilities.<sup>1</sup>
- Predators target people with ID because they know they are easily manipulated and will have difficulty reporting or testifying. The crimes and abuse go mostly unrecognized, unprosecuted, and unpunished. And the abuser is free to abuse again.<sup>1</sup> Police and prosecutors are often reluctant to take these cases because they are difficult to win in court.<sup>1</sup>
- Individuals with ID or ASD are more likely than others to be assaulted or abused by someone they know. The incidents happen in places where they are supposed to be protected and safe, often by a person they have been taught to trust and rely upon.<sup>1</sup>
- All forms of abuse (verbal, emotional, physical, sexual, or financial) among individuals with ID are underreported. About 60% of individuals with ID have communication and language difficulties<sup>2</sup>, some are non-verbal. Due to the preponderance of poor communication skills, the rate of all forms of abuse to the ID and ASD community is likely much higher than what is reported.

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<sup>1</sup> Source NPR Report January 2018

<sup>2</sup> NIH



## Proposed Solutions:

- First, we want Hearings whereby legislators listen to individuals and families experiencing the abuse. Legislators need to understand the extent and seriousness of the problem within their own districts. We want Hearings that lead to legislation or regulations that reduce incidents. Such as:
  - Require mandatory use of technology to reduce neglect and abuse. Currently video monitoring with audio and night vision in licensed or unlicensed settings can greatly reduce incidents of abuse and neglect. Technology will evolve and offer more options over time. The rights of individuals with ID and ASD, including the right to privacy, should be preserved to the greatest extent practical.
  - Emphasize the need to comply with the CMS HCBS Final Rule to implement accommodations and practices that include the person and their family at the center of every consideration and decision that may or does affect them. This includes the individual and their family updating the ISP to request technology or other safeguards without fear of reprisal or loss of services.
  - Ensure everyone has access and support to own their communication. Mandating this, as we do for other aspects of a person's support is critical and should not be left to the provider to assess and approve. If it's in the ISP, Providers must be properly trained and deliver the service.
  - Develop and maintain an Abuse Registry of caregivers who have been terminated for reasons of neglect or abuse, and/or exploitation, similar to the law passed in [Massachusetts](#) in February 2020 with unanimous House, Senate, and Administration support.
  - Increase provider accountability and transparency. Providers currently self-report and investigate incidents under the [6400 Regulations](#), much to the disapproval of self-advocates and families. Investigations should be independent and conflict free.
  - Enact regulations, for the decade old, PA [2010 Adult Protective Services Act. This act](#), put in place to protect adults aged 18-59 with disabilities, needs governing regulations to carry out its protections.

## **September 22<sup>nd</sup> Testimony**

**by Debbie Robinson and Suzanne Erb**

Speaking for Ourselves is a grass-roots, non-profit organization composed of people with developmental disabilities.

Our purpose is to help our members run their organizations, develop leadership skills through real-life experiences, learn to work together collectively to address their own issues, and increase their own self-sufficiency and independence.

Speaking for Ourselves began in February 1982 and has been assisting to empower others, pass legislation, and supporting all people to speak for themselves. We are 40 years strong and continue to uphold the beliefs of our founders.

As an organization dedicated to making sure that people with disabilities are able to speak for ourselves, we value the ability to be involved in our communities.

During the pandemic, our ability to stay involved in our communities has been threatened. Many of us have felt isolated, and have not been able to keep up with family and friends. Many of us have turned to technology in order to reach out and touch someone, so to speak, using Zoom and other meeting platforms. For some of us, technology has helped us find and use our voice, even during these challenging times.

Meet Debbie and Suzanne. Both of us use assistive technology to live our lives in different ways. Debbie uses a wheelchair to navigate the physical world, and Suzanne uses assistive technology to navigate the web. Both of us rely on assistive technology in order to live our lives and to have a voice in our communities.

Many people with disabilities are not able to have this same opportunity. For them, the ability to navigate the world and the web is only a distant dream.

There are many issues that stand in the way of people who want to participate in their communities. poverty, lack of training, poor connectivity, all of these contribute to the inability of people to access assistive technology.

Imagine a state where people like Debbie and Suzanne can participate fully in and contribute to their communities. Imagine a state where they can use tele-medicine, tele-work and online shopping easily. Imagine a state where anyone who has a disability can live a full life. This is the Pennsylvania we all want.

But in order for this picture of Pennsylvania to become a reality, we need to have adequate funding for organizations like TechOWL and PATF, so that they can help people with disabilities to communicate, travel, read and write and contribute to our communities.

Thank you for the opportunity to testify at this hearing.

Testimony of Kim Singleton  
Senior Director of Assistive Technology Programs  
Institute on Disabilities at Temple University

Public Hearing on the  
Interaction of the Disabled Community with Technological Innovation  
Pennsylvania House Democratic Policy Committee Hearing  
September 22, 2022

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## Introduction

On behalf of TechOWL at the Institute on Disabilities, I would like to thank Chairman Bizzarro, Representative Hohenstein, and other members of the Pennsylvania House Democratic Policy Committee for convening this hearing on the Interaction of the Disabled Community with Technological Innovation. Thank you for allowing us to share our insights and experiences on this critical issue for Pennsylvanians with disabilities. I am Kim Singleton, Senior Director of Assistive Technology Programs at the Institute on Disabilities at Temple University. In this role, I direct TechOWL - Pennsylvania's Assistive Technology Act Program as well as other assistive technology focused programs and projects in the Commonwealth of Pennsylvania.

TechOWL is Pennsylvania's federally designated Assistive Technology Act (AT Act) program and part of The Institute on Disabilities at Temple University. The Institute on Disabilities encompasses TechOWL as well as Pennsylvania's University Center for Excellence in Developmental Disabilities Education, Research and Service (UCEDD)<sup>1</sup>. This structure benefits Pennsylvania by offering a blend of direct service, academic, and research disability programs and projects. While housed at and supported by Temple University, TechOWL is an "outward facing" statewide program – serving all of Pennsylvania.

The TechOWL team is richly diverse. We are a mix of people with lived disability experience, licensed professionals, project coordinators, specialists, and consultants. The primary office is at Temple University, and we have eight additional regional resource centers through contracts with other disability organizations. This arrangement allows TechOWL to provide local services to thousands of disabled Pennsylvanians. The TechOWL team is fortunate to be able to listen and learn from disabled Pennsylvanians – informing our perception and practice.

Today, I hope to share the TechOWL team's perspective regarding the met and unmet assistive technology needs in Pennsylvania.

### Who are disabled Pennsylvanians?

People with disabilities include senior citizens, veterans, people experiencing mental illness, people with chronic illness, children, and other school-age youth, etc.

Because disability represents natural human variation, disability impacts all of us. If each of us lives long enough, we will age into disability. Over our lifetime, most of us will experience at least one physical or mental condition that substantially limits us in some way.

In addition to disabled Pennsylvanians, other people touched by disability include family and friends, direct support professionals, teachers, administrators and leaders, veterans, senior citizens, and others.

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<sup>1</sup> The US Department of Health and Human Services, Administration on Community Living) funds the UCEDD to work toward a vision of self-determination, independence, productivity, and community inclusion for people with disabilities throughout their lifespan.

TechOWL serves all Pennsylvanians touched by any disability - at any time in their lives. We are shoulder to shoulder with disabled Pennsylvanians, often navigating siloed social services and systems.

## What is Assistive Technology?

The definition of “assist” is to “give support or aid.” Doesn’t all technology give support or aid the user? We use technology, tools, or gadgets to aid us when we do things. When we talk about assistive technology, we use the word “assistive” to give information about the **user** of the technology, tool, or gadget. Assistive technologies are used by, or for, people with disabilities.

The federal government defines assistive technology as “Any item, piece of equipment or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve the functional capacities of individuals with disabilities.”<sup>2</sup> AT includes the services necessary to get and use the devices, including assessment, customization, repair, and training.

### *Accessible Definition of AT*

*An assistive technology (AT) device is anything used by a disabled person to do things. AT makes tasks easier – or even possible. People can buy AT from a company, have it made, or change it to fit a need.*

*An AT service is any service which directly helps a person with a disability with an AT device. An AT service can help in choosing, getting, or using an AT device.*

People use “enabling technology,” “adaptive technology,” or “assistive technology” interchangeably. “Supportive technology” refers to technology used by other people to increase or improve the functional capabilities of a person with a disability.

Today, AT is varied. It can be as simple as a big key holder or modified spoon. It can be as complex as eye-gaze technology, screen readers, and standing power wheelchairs. AT is a blend of specialized and mainstream tools. As mainstream technology becomes more sophisticated, developers integrate accessibility features into the design. We see examples of this in computers, smartphones, voice activated devices, smart home technology and more. Specialized tools refer to those devices created specifically for disabled users.

The fabrication of AT is a quickly growing area. With common household materials, we can make AT. Cardboard carpentry, 3-D printing, casting and molding, and PVC construction are all emerging as part of the AT landscape.

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<sup>2</sup> Assistive technology was first defined in the “Technology-Related Assistance for Individuals with Disabilities Act 1988 at this link <https://www.congress.gov/bill/100th-congress/senate-bill/2561/text>

## What is an Assistive Technology (AT) Act program?

The federal government originally passed the AT Act in 1988 to help increase awareness of AT, access to AT, and acquisition of AT. It was last reauthorized in 2004 and this reauthorization also authorized and described a set of state level and state leadership activities for State AT Programs to implement.<sup>3</sup>

Each state has flexibility to meet the needs of their citizens. The Institute on Disabilities at Temple University has been the Pennsylvania designee since 1991.

TechOWL's mission and mandate is to ensure that all disabled Pennsylvanians can:

1. Imagine and dream of the increased independence and function they can have with technology, tools, and gadgets.
2. Discover and find potential devices to meet their personal goals.
3. Explore and try the actual devices that might meet their needs.
4. Decide on specific technologies, tools, and gadgets.
5. Get the things they need to live their best lives.

## Assistive Technology in Pennsylvania

**Imagine** – Like many of us, Pennsylvanians with disabilities must transcend cultural expectations and personally imposed limitations to imagine possibilities for themselves.

To see personal potential, disabled Pennsylvanians need authentic representation in all parts of today's society. We need to hear their voices.

What does the potential AT user want to do? Get dressed? Eat independently? Wash the dishes? Buy things? Care for others? Work? Learn? Go to church? Volunteer? Relax and play? Communicate with others? These are all examples of activities from the US Bureau of Labor and Statistics' 2021 Americans Time Use study gives us an idea of what activities Americans spend their time on. Not disabled Americans – all Americans.<sup>4</sup>

Through our impressive social media and online presence (@TechOWLpa), we help people dream. We show them things they did not know existed. We ignite curiosity. We amplify disabled voices. We use accessible language and create accessible content. Through our outreach, presentations, and technical assistance, we strive to guide organizational thinking about AT.

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<sup>3</sup> You can find more information about the requirements and mandates of the AT Act at <https://at3center.net/at-act-information/>

<sup>4</sup> More information about the 2021 Americans Time Use study is at [https://www.bls.gov/news.release/archives/atus\\_06232022.htm](https://www.bls.gov/news.release/archives/atus_06232022.htm)

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Pennsylvanians impacted by disability contact us through our on-line chat, social media messaging, email, and our toll-free phone number.

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**Discover** – Because technology is rapidly changing all the time, people need to know about current and innovative technologies.

Our organization listens to Pennsylvanians with disabilities and suggests AT that might work for them. As we say “You know you. We know stuff.” Part of our job is to stay up to date with technology innovations and state-of-the-art devices.

### *Discovering New Solutions*

*Last year, Dan and his wife came in for a demonstration of possible assistive technology solutions for Dan to access both his computer and phone. He was extremely interested in moving a computer mouse with his head, face, or eyes. We demonstrated two different types of head tracking software and a head tracking mouse. He really liked the head tracking mouse much more than the other options. We also hooked up his phone to a switch interface with 2 buttons which drastically increased his speed of use of his phone. He was really getting the hang of it after the two-hour demo. We registered them for a loan of all the devices that they wanted to continue to trial.*

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**Explore** – When a potential AT user is curious about a device, tool, or gadget, they need to try it. They need to see if it would work for them.

Pennsylvanians with disabilities are lucky because we have a statewide Assistive Technology Lending Library (ATLL) annually funded in the state budget. Anyone touched by disability in the Commonwealth can borrow items from the ATLL. We drop ship the item(s) directly to them from our centralized inventory in Camp Hill and an AT specialist will reach out to provide support. Borrowers can try devices for 3-9 weeks (depending on the item and waitlists) to see if the AT solution will work for them. When borrowers have this opportunity, we increase the likelihood that, once obtained, an AT user will successfully incorporate the AT in their lives.

Borrowers need technical support – especially for complicated devices. We strive to give borrowers the support they need with limited staff and time.

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**Decide** – After discovery and exploration, Pennsylvanians with disabilities need to consider many factors when deciding about AT.

Sometimes, disabled Pennsylvanians need guidance to make the best decision. For example:

- What is the learning curve for the device? They need to consider tech support and learning needs.
- How will they maintain and repair the device? For instance, it takes about 4-6 months for a wheelchair vendor to repair a wheelchair.
- What is the back-up plan when it is not available?
- Does it require internet access?
- How adaptable is the AT to address changing needs? Typically, AT funding sources will only consider an upgrade every 3-5 years.
- How will the device get funded?

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**Get** – How can a person get what they decided that they need?

One significant barrier to obtaining AT is the cost. School districts own the AT provided by the school and often the AT must stay at school. Getting AT funded through insurance, state programs like the Office of Vocational Rehabilitation or waiver programs is confusing and the process is lengthy. Did you know that insurance usually does not cover vision devices (other than glasses and contact lenses) and hearing aids? Home and auto modifications are frequently not covered. Funding for speech-generating devices often requires authorization activities that are more expensive than buying the components from public vendors.

To help make it possible for disabled Pennsylvanians to get what they need, TechOWL operates a variety of programs and projects. These programs include:

- PA's Free Special Phone program - The Telecommunication Device Distribution Program uses a TRS surcharge on your phone bill to get equipment for eligible Pennsylvanians.
- PA's iCanConnect Program – The National Deaf-Blind Equipment Distribution Program provides equipment to make communication and the internet accessible for people with both hearing and vision loss.
- AT Reuse – Through this program we collect, repair, and sanitize gently used AT and give it to another Pennsylvanian.
- Connect with Tech – Funded by the Department of Health, this helps Pennsylvanians at risk for health inequity to get a device, connect to the internet, and support in learning to use the device.
- Fabrication – Using 3-D printing, PVC construction, etc. we make AT for Pennsylvanians at no cost to them.
- The Virginia DelSordo Fund – Seeded by a small bequest from a former team member, this fund provides small awards as a “last resort” for disabled Pennsylvanians to get AT. This fund is dwindling as we are distributing grants with no replacement funding.

When appropriate, we refer to other funding sources such as other grant opportunities, health insurance, Medicaid, Medicare, crowd-sourcing platforms, and Pennsylvania's Assistive Technology Foundation. We do not receive funds from the state to provide cash loans to individuals or families.

### From a woman in Curwensville to Connect with Tech

*"Thank you so much for the wonderful surprise delivered at my door. Immediately, I began to rip open this mysterious package just like an excited five-year old does on Christmas morning. To my delight, what I found was so much better than what came from the boxes grandma sent. This tablet will connect me to old friends and new friends. It will open doors to new ideas, possibilities, and knowledge; and it will enlighten my days in a hundred ways that I never imagined. Please convey my thanks to everyone involved in providing the tablet."*

### From a parent about Reuse

*In central Pennsylvania, R.H. saw our AT Regional Center's Facebook post for an 18-inch special Stroller available through the reuse program. Her daughter currently had a special stroller the next size down but was quickly growing out of it and they were not able to afford a new stroller. The family picked up the special stroller from our AT Regional Center. They said it was the perfect size for their daughter. In exchange, they donated their current stroller that was in good condition and that stroller has also found a new home.*

## Summary and Recommendations

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We are in a pivotal time to meaningfully impact Pennsylvanians with disabilities regarding assistive technology. You make a difference. Please consider the following recommendations.

- Encourage integration and streamlining of state support systems.
- Change the language of the line in the state budget from "Assistive Technology Demonstration and Training" to "Assistive Technology Activities for Pennsylvanians." This change will allow us to maintain a robust AT Lending Library and efficiently provide AT directly to Pennsylvanians.
- Increase the line in the state budget (currently \$437,625) by \$550,000. This increase would ensure that Pennsylvanians can borrow current AT (additional \$100,000) as well as augment the dwindling last-resort DelSordo Fund (\$450,000).
- Support the "Right to Repair" legislation found here <https://www.legis.state.pa.us/cfdocs/billinfo/billinfo.cfm?year=2021&sind=0&body=S&ty pe=B&bn=998>. This legislation directly addresses a barrier to maintaining working AT such as wheelchairs.

Pennsylvania House Democratic Policy Committee  
*Policy Hearing: Interaction of the Disabled Community  
with Technological Innovation*  
September 22, 2022

Testimony of  
Dr. Emily Shea Tanis  
Principal Investigator, State of the States in Intellectual and Developmental  
Disabilities Longitudinal Data Project of National Significance and  
Associate Professor, Kansas University Center on Developmental Disabilities,  
Life Span Institute

Good afternoon, Chairman Bizzarro, and members of the committee. I want to thank Representative Hohenstein for hosting this hearing to discuss the advancement of the rights of people with intellectual and developmental disabilities and their families to access technology solutions and meaningfully participate in the natural routines and rhythms of American society.

My name is Shea Tanis. I am a Professor at the Kansas University Center on Excellence in Developmental Disabilities housed in the KU Life Span Institute. The Life Span Institute has been leading research on intellectual and developmental disabilities for over 60 years. I am also the Principal Investigator of the State of the States in Intellectual and Developmental Disabilities Longitudinal Project of National Significance, a project funded through the U.S. Administration for Community Living that tracks public expenditures for intellectual and developmental disability (IDD) services and supports. For over 40 years our analyses have demonstrated the trends and impacts of fiscal policy nationally and within the states. I am also the past Director of the Coleman Institute for Cognitive Disabilities where, for over a decade, my work focused on catalyzing and integrating advances in technology to promote the quality of life of people with cognitive disabilities. But the most important hat I wear is not my professional hat, but that of a sibling ally to my brother with acquired brain injury who experiences daily the inequitable social and physical architecture of society for people with disabilities. It is through these lived and learned experiences that I contend that the most disruptive and transformational outcomes in quality of life for people with IDD in the 21st century manifest from new opportunities to engage with technology solutions.

In 2013, nearly a decade ago, the Coleman Institute Annual Conference engaged distinguished legal scholar, Thomas Gilhool to substantiate the parallels between the right to education and the right to community living, to the right to technology. Mr.

Gilhool needs no introduction in this city where he was the Pennsylvania Secretary of Education, Chief Counsel for the Public Interest Law Center, and a driving force behind not only Free and Appropriate Public Education for children with disabilities through the PARC v. Commonwealth of Pennsylvania case, but also a prime catalyst in the movement toward community-based services through the Halderman v. Pennhurst settlement. In his concluding remarks at the conference, Mr. Gilhool stated:

“There is an easy way to close, and it is to return to Lincoln [Abraham]. For those of you in this room, the scientists, the engineers, the entrepreneurs, the inventors, the members and leaders of the movement for the freedom and full realization of the capabilities of people with disability - YOU, as Lincoln said, have it within the power of your imagination and your bold and courageous action to create the *circumstances which will now permit* the Constitutional requirement of decent equality and access as others functionally, and as good as others, to defining technologies.”

Following Thomas Gilhool’s keynote speech, our institute, along with thought leaders from across the disability community, penned the Declaration on *The Rights of People with Cognitive Disabilities to Technology and Information Access*. It is a statement of principles outlining the expectations of available and equal access to not only the ubiquitous technologies of today, but the disruptive technologies of tomorrow. Over the years, we have seen a statewide adoption of the Declaration through legislative policy, but more prolific has been the demonstration of its principles through the advancement of Technology First initiatives across the United States.

Technology First began in Ohio in 2017 as a movement but quickly transformed into a statewide “framework for systems change where technology is considered first in the discussions of support options available to individuals and families through person-directed approaches to promote meaningful participation, social inclusion, self-determination, and quality of life” (Tanis, 2019).

Our team at the University of Colorado, now at the University of Kansas, has tracked the data and engaged in the design and implementation of Technology First as a vehicle for realizing *The Rights of People with Cognitive Disabilities to Technology and Information Access* in practice. In five short years, Technology First initiatives have advanced in twenty-two states - one of the most expeditiously adopted systems change efforts in our field today. Why has it been adopted so quickly across the U.S.? Our research conducted with partners at the National Association of State Developmental Disability Directors demonstrates that Technology First is championed because it addresses the most pressing challenges of our field today. First, it promotes autonomy, self-direction, and community integration for people

with IDD that are the pillars of disability rights. Second, it addresses the direct care workforce shortages plaguing our states and nation. Finally, the use of technology solutions drives more cost-efficient and effective practices (Brent & Tanis, 2020). When asked if states were interested in advancing Technology First back in 2019, 88% of states responded “yes.” The remaining 12% of states indicated they just needed more information.

In 2020, when we surveyed intellectual and developmental disabilities (IDD) service providers from across the nation through the Association of Community Options and Resources (ANCOR), we found comparable results with 78% of providers of all sizes in thirty-eight states indicating they wanted to advance Technology First in their state. The remaining 22% needed more clarity around defined outcomes of Technology First (Tanis, 2021).

It was clear even before the height of the COVID-19 pandemic, that the advancement of technology solutions to access community living was essential. However, what we learned because the pandemic, was that opportunities to engage with technology and information was critically essential for human survival. Without access to mainstream information about variables such as availability of personal protective equipment (PPE), regional confirmed cases, and access to vaccines, having an intellectual disability was the “strongest independent risk factor for presenting with a COVID-19 diagnosis and the strongest independent risk factor, other than age, for Covid-19 mortality” (Gleason et al., 2021). However, there were those who had an advantage as the pandemic took hold, and it was Technology First states that had already laid the foundations to pivot and respond to the crisis using tools of the modern age such as remote supports, digital communications, and environmental sensors.

Technology First states have demonstrated legislative priority to equity, modernized and harmonized policies, addressed technology solutions through person-directed approaches, and made available information about technology accessible through training.

Pennsylvania has already begun the challenging work of initiating Technology First through several systemic component elements, but what remains is a statewide commitment through policy and dedicated resources to ensure that people with cognitive disabilities are central to the development and advancement of technology solutions. Without this investment we place the community at risk for falling further behind and exacerbating the digital disability divide, health disparities, and information access.

I will conclude by returning now to Thomas Gilhool who shared that access to technology and information was fast becoming the equivalent of access to education

for this generation, and for future generations it was even more critical possibly rivaling the centrality of educational access for persons in our society.

Technology First is a path to realizing the right to technology and information and the empowerment of people with cognitive disabilities.

I thank you for your consideration and will be happy to respond to questions of the committee.

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September 12, 2022

House Democratic Policy Committee  
PA House of Representatives  
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Representatives;

Thank you for extending an invitation to speak to you today. Today's theme, "Interaction of the Disabled Community with Technological Innovation" is such a vitally important one. I am sure many of my colleagues on this panel before you today will talk about how the rapid advance of technology is both affirming of their independence and maddeningly frustrating when it leaves us behind.

I will take a different tack with my comments today. That is, we often look at the technology from the perspective of the devices we hold in our hands, or perhaps we use to connect with other humans, or even the underlying services that are empowered by the devices. But we often forget that in many ways, it's far more important to make sure that the technological teams that are developing these tools include people with disabilities at every stage of product development.

There are very few technologies that people with disabilities use every day that were expressly designed for them. A hearing aid, JAWS readers, captioning, mobility aids, are examples of technologies that were purpose built for people with disabilities.

What's far more common, at least within parts of the disability community, is technology is NOT developed for people with disabilities but yet, they are adopted with incredible speed by segments of the population simply because there is no other alternative.

An example from the Deaf and hard of hearing community may seem fairly recent but in technological terms, it happened eons ago. In 2013, an Israeli company released "Glide". This was a new idea: something that a person could record a brief message and send to someone else. Not a new idea, we have texts... but having a platform do that for videos seamlessly was new.

In short order, the platform became huge in the Deaf and hard of hearing community. People could now sign in, find their friends and acquaintances online, and send short video messages using ASL that wasn't limited to 160 characters.

To its credit, the folks behind the Glide app recognized how their program was being used. Along with their “spokesperson” Sarah Snow, they created an environment that developed features that catered to this community. All of that came to a halt in 2016 when the company seemed to decide to go in a different direction.

By then the cat was out of the bag: similar products popped up and even the big social media companies offered similar means of communication.

These “accidental” uses of technology are rare but they have deep applications for our community.

However, I invite you to think about the people who work in these technological fields. It’s tempting to think of them as 1990’s stereotypical hackers: sun-starved, socially awkward males subsisting on a diet of takeout pizza and energy drinks.

The reality is that the field does not match that stereotype except it is overwhelmingly male, overwhelmingly white, and underwhelmingly disabled.

Statistics are difficult to come by. Most companies do not highlight disability hiring trends in their Inclusion and Diversity reports. For example, Apple’s latest report: <https://www.apple.com/diversity/> talks about the rates of women and racial differences but nothing of disability.

This lack of inclusion has stark impacts on people with disabilities.

For starters, the most immediate impact is the lack of employment opportunities for this community. In an environment where 63.7% of non-disabled people are employed, for people with disabilities, that’s just 19.1%

But far more important is the experience of the Deaf/Disabled community becomes part of the product lifecycle and products are designed that just make sense.

Earlier this year, I was asked to assess a tool that would vibrate on different parts of the body depending on the characteristics of the music being played. A low pitched sound triggered a vibration on my torso while a high-pitched sound would be felt on my wrist and ankles.

A very cool concept to be sure, but when I asked the question: “Were any Deaf people actually involved in developing this product?” The response was “No.” And I knew what the answer would be because if you asked me as a Deaf person “does this scheme make sense?” I would’ve said “No, it’s not intuitive because no Deaf person I know would’ve forced a user to learn an entirely foreign concept for using vibrations on their body.”

This leads us to “what can this committee do?”

The Commonwealth of Pennsylvania, as a major purchaser of technology, can make a difference in this regard. They can, for example, follow the example of the US Government where in 2014, the Office for Federal Compliance Contract Programs (OFCCP) implemented a requirement that major contractors in the Federal family must show they are hiring people with disabilities within their workforces. <https://www.dol.gov/agencies/ofccp/faqs/section-503>

The Commonwealth is also a consumer and developer of technology. Again - statistics are difficult to come by. The Office of Administration-Human Resources data does not identify disability in its reports. But increasing the number of employees in state governments with disabilities will represent a powerful shift, not only in the user experience of the technology, but also in developing the standards and requirements for future technology.

It's far too easy to build applications that comply with Section 508 rules for accessibility. That's how most contracts are done today. It's a very different equation when the person with a disability has a voice in the contracting process and is able to articulate their needs throughout.

And this solution solves many existing problems in our community today. By changing the person with a disability from a simple end-user to an invested team member - the products will become better and more inclusive in the end.

Thank you for giving me this opportunity to present testimony to the committee.

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Enc.