

**AGING AND DISABILITY IN THE
21ST CENTURY: HOW TECHNOLOGY
CAN HELP MAINTAIN HEALTH
AND QUALITY OF LIFE**

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WEDNESDAY, MAY 22, 2019

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

The Committee met, pursuant to notice, at 9:33 a.m., in Room 562, Dirksen Senate Office Building, Hon. Susan Collins (Chairman of the Committee) presiding.

Present: Senators Collins, Tim Scott, Braun, Casey, Sinema, and Rosen.

**OPENING STATEMENT OF SENATOR
SUSAN M. COLLINS, CHAIRMAN**

The CHAIRMAN. The hearing will come to order.

Good morning. Today we will explore how 21st century technology is improving the quality of life for older Americans and those with disabilities. We have on display an array of devices that are available today. I want to show you a few of them from up here on the dais.

This pen, for example, is the PenFriend 2. It allows one to put stickers on various items and then record voice labels in order to identify them later. This is particularly helpful for people with limited vision.

For example, let us say that there are a number of cans in your kitchen cabinet. One might be pears, one might be corn, one might be peaches. They are all about the same size, and it can be difficult for someone with limited vision to be able to discern which is which.

Well, when the cans of corn, peaches, and pears are bought, each would have one of these yellow stickers put on them, and then using this device, you would record what the item is. Later on, when the person with limited vision is trying to select the right can, he or she can simply touch the pen to the yellow stickie, and it will tell him or her what it is. That is just one of the many examples.

Another are spoons that make it easier for people who have Parkinson's, for example, to continue to feed themselves. Or there are other mobility issues, this intriguing spoon, if I can make it work here, will bend to come to the right level of your mouth, so there is so much that is exciting out there.

These days, most of us carry in our pocket at least one device, such as my iPhone. This phone, while still used for making telephone calls, today offers so much more potential. A typical smartphone can track health measures like daily steps or blood sugar and can pair with other devices to predict the risk of falls or diabetic episodes.

From the everyday technologies that we all use to assistive technologies that help seniors and those with disabilities improve function, these devices are poised to change the future of aging. Survey after survey indicates that seniors envision themselves living independently at home in their own community for as long as possible and living their lives to the fullest. Technology can help make that possible.

With 10,000 Americans turning 65 every day and one out of five Americans set to join this group by 2035, we are in the midst of a major demographic shift. The fastest-growing segment of our population are Americans age 85 and older. While aging brings opportunity, it also comes with increased risk of multiple and interacting health conditions that can lead to disability, at times requiring long-term care, and making it more difficult to age at home.

As our population is aging, the need for care and support is increasing. In 2010, there were approximately seven potential caregivers for each person over age 80. By 2030, there will be only four, and by 2050, the number drops to fewer than three, so more people will have to rely on fewer caregivers—opening the door for technology to help fill that gap.

Advances in technology are working to bridge this “care gap,” improving function in activities of daily living, helping to manage multiple chronic conditions, reducing the risk of hazards, and making homes safer for seniors. Not only has technology allowed seniors to age in place, but also it is making it possible for individuals to move out of nursing homes or other institutionalized settings back into the privacy, security, and comfort of their very own homes.

Through tools and technologies, Maine’s Homeward Bound program, for example, has helped to transition seniors as well as others with disabilities back into their communities, and we will hear more about that this morning.

One particularly promising avenue for new technologies is in the prevention of falls. Falls are a leading cause of both fatal and nonfatal injuries among seniors and are projected to cost our Nation \$67 billion in the coming year alone. Falls-related injuries can have a devastating impact, requiring round-the-clock institutional care, but new technologies can reduce the risk of falls, as well as contact emergency services for help as soon as a fall happens. I am excited about an innovative approach now being developed by the University of Maine, which is a pair of smart glasses that can detect edges, such as stairs or curbs, to help prevent falls, particularly for those seniors with limited mobility and limited eyesight.

Another area where technology holds great potential is in reducing social isolation. Social media and video chat on tablets and smartphones help to reduce isolation and loneliness and enrich seniors’ lives by keeping them connected to their loved ones. We have had previous hearings on the health impact of prolonged isolation,

and they are substantial, on physical, emotional, and mental health and well-being. In fact, according to researchers, prolonged isolation is comparable to smoking 15 cigarettes a day. That is how profound the impact on health is. While not a substitute for interacting directly with people, technology can help bring people together.

It is important that older Americans have a key role in developing these technologies. That will increase utilization, reduce stigma, and ultimately makes for a better product.

Older Americans also have helped companies realize that they want technology devices that look just like those that are used by younger generations. For example, many of us are familiar with hearing on television that old phrase, "I have fallen, and I cannot get up." Well, that was an advertisement for a medical alert system that, for many years, was considered among the most advanced technologies to help seniors age in place. While many seniors still successfully rely on this device, breakthroughs in modern technology have brought new options that are far more versatile.

Technology is opening the doors for older Americans and those with disabilities to live the way they prefer, and that really is what this is all about—accommodating the individual preferences as we grow older. From better managing health and mobility to increasing connectivity and community involvement, technologies on the market today and those on the horizon for tomorrow promise to usher in a new era of aging.

I look forward to hearing our excellent witnesses today, and I now will turn to our Ranking Member for his opening statement. Senator Casey.

**OPENING STATEMENT OF SENATOR
ROBERT P. CASEY, JR., RANKING MEMBER**

Senator CASEY. Chairman Collins, thank you for your testimony, and also thank you for this hearing.

Assistive technology provides an opportunity for millions of individuals to live independently. It can improve the lives of older Americans and people with disabilities, and today we will hear how assistive technology can help members of these communities enjoy the same rights as any individual. We will hear how it gives everyone the right to learn. We know that assistive technology makes it possible for students with disabilities to fully participate in their education.

We will hear how it gives everyone the opportunity to work, and we know that assistive technology can break down barriers to employment and allow individuals to remain in the workforce as long as they choose to. We will hear how it gives everyone the right to live independently. Assistive technology provides the opportunity for older adults to live and thrive in their own homes and communities, and as a previous witness who testified before this committee, Rick Creech from Pennsylvania, explained, assistive technology gives everyone the right to be heard.

As Chairman Collins and others will recall, Rick testified before the Committee with the assistance of an alternative communication device. Without that communication device, someone like Rick might have used a spelling board or may not have been able to

communicate much at all. He told the Committee at that time, “living without being able to communicate was like being behind four glass walls.”

This hearing will examine how assistive technology can break down those walls. We hope to raise awareness about the availability of assistive technology for those who could benefit and highlight that far too many people with disabilities and older adults still need access to assistive technology.

I also hope this hearing will jump-start a conversation in Congress about updating the Assistive Technology Act, a law passed way back in 2004 that needs an update. Technology looked a lot different than it does today. Just think of our smartphones—kind of mini computers that we all carry around. Certainly older adults never imagined the ability of Fitbits or smartwatches to promote healthy living. None of us could have imagined that.

People who are blind or have limited vision—as Chairman Collins pointed out—did not imagine they could wear glasses, literally wear glasses that were connected by Wi-Fi to someone who can see what is around that person and communicate the way to get to a restaurant, a theater, or a grocery store. Every week there are new advances that we must harness so that every American who requires assistance can, in fact, benefit.

It is for this reason that Senator Collins and I will be introducing the 21st Century Assistive Technology Act when we return from recess, a bill that can, quite literally, bring assistive technology into the 21st century. This legislation will update the Assistive Technology Act to provide more resources to State assistive technology programs that would expand access for older adults and individuals with disabilities.

I will also introduce the Access to Freedom of Speech for All Act that will increase access to information about alternative communication devices for those who have speech and written language disabilities, areas that often limit an individual’s access to education and employment.

These bills are designed to ensure assistive technology and alternative communication devices are available to those who need it so they can be full participants in every aspect of their lives, and to help us make the case, I am pleased that we can showcase here today, in the back of the room, the types of assistive technology that we want to get into the hands, or in some cases be the hands, of seniors and people with disabilities.

So, again, I want to thank our witnesses and thank Chairman Collins for agreeing to hold this hearing today. We look forward to the testimony of our witnesses.

Thank you.

The CHAIRMAN. Thank you very much, Senator. I want to welcome Senator Rosen, who is here today, and I am sure there will be other Senators in and out, which is pretty typical of our hearings.

I have asked the staff to also put out some more of the technology in front of us that I referred to in my opening statement, and I would invite people after the hearing to come up and take a look at it, supplementing what Senator Casey said.

We are delighted now to turn to our distinguished panel of witnesses.

First we will hear from Dr. Joseph Coughlin. Dr. Coughlin is the founder and Director of the AgeLab at the Massachusetts Institute of Technology. He studies the role of technology in the lives of the 50-plus population, and what better place to do that than at MIT. He is also author of the "Longevity Economy: Inside the World's Fastest-Growing, Most Misunderstood Market."

Next we will hear from Cara McCarty. Ms. McCarty is the director at the Cooper Hewitt, Smithsonian Design Museum, which houses exhibits featuring an array of assistive technologies for older adults and those with disabilities. We welcome you as well.

I am, of course, particularly pleased to introduce our third witness, Brenda Gallant from Maine, the great State of Maine. Brenda is the executive director of Maine's Long-Term Care Ombudsman Program, and she directs the Homeward Bound program that I mentioned in my opening statement. Sponsored by Maine's Money Follows the Person, this program provides participants with the tools and technologies necessary to transfer from living at a nursing home or other institutionalized setting back into their own communities and their own homes.

Finally, I am delighted to turn to our Ranking Member to introduce our final witness.

Senator CASEY. Thank you, Chairman Collins.

I am here to introduce today Bob Mecca from St. Marys, Pennsylvania, Elk County, which is a pretty good drive from here, as we were talking before the hearing about the drive he had. He drove down, and his wife, Dawn, did some driving when she got here. I guess it is up for grabs who is driving home, right? But we are grateful you are here, and Bob will be able to speak personally about the importance of assistive technology. He is one of the millions of people in our country who use assistive technology every day in order to maintain their independence. Not only is Bob a user of assistive technology, he helps provide assistive technology to individuals in some of the most rural counties in Pennsylvania.

Bob is the executive director of Life and Independence for Today, an organization that serves the needs of Pennsylvanians with disabilities in Cameron, Clearfield, Elk, Jefferson, McKean, and Potter counties, and take my word for it, that is a lot of territory in just those counties, and as I mentioned, his wife, Dawn, is with him. We are thankful they are here and that they made the journey here, I guess about 4-1/2 hours one way, so we are grateful for that effort that you have made and look forward to your testimony.

Thanks.

The CHAIRMAN. Thank you very much.

Dr. Coughlin, we will start with you. Thank you.

**STATEMENT OF JOSEPH F. COUGHLIN, PH.D.,
DIRECTOR, AGE LAB, MASSACHUSETTS INSTITUTE
OF TECHNOLOGY, CAMBRIDGE, MASSACHUSETTS**

Dr. COUGHLIN. Thank you so much, Chair Collins, Ranking Member Casey, and Committee members for the opportunity to discuss how technology will not just improve aging and quality of life for

older adults and their families, but it is actually a new opportunity to redefine how we age in the future.

While I am also privileged to serve on the National Board of AARP, I am here today as a private citizen and as a research scientist and director of the MIT AgeLab. I have collaborated for decades with researchers around the world, and it is on their shoulders that I make a few of these remarks, and particularly enjoy the fact that this is Older Americans Month that you chose to have this hearing.

Senator Casey, I want to start with a resident of Pennsylvania that you may recall to set my remarks. Sarah Knauss lived to 119 years old in Pennsylvania, and she was asked, if you can believe this, on her 115th birthday, “Why do you enjoy living so long?” That took a lot of chutzpah, I must add, by a journalist, but she came back with an answer better than any scientist, any engineer, any policymaker: “I enjoy my life because I have my health and I can do things.”

Members of the Committee, technology is not just to help people age. We have an opportunity now to set a new longevity economy, to change how we age, to change how we live.

Unfortunately, we are constrained by a short story. Unfortunately, the short story is that old age is about frailty. It is about what we cannot do. It is about poverty. It is about poor health, and that is absolutely true for a very large number of people, but it is also a time for us to think of something else. It is no longer the aging ticking time bomb as many have described it.

Unfortunately, that story has permeated the consciousness of technology makers, so where we have companies where the average age is in their 30’s and in some cases their 20’s, they see someone in their 40’s as being old, but more importantly, the story that they see is the only thing you do in older age starting at age 50, 60, 70, and 80 is to be reminded to take your medications.

So as a result, with all the great technology and promise that we have there, we have technologies that may be functional, but they are big, they are beige, and they are boring, so they lead to stigma, if you will, by anyone who chooses to use them when, in fact, we do not want TV remotes that are large enough to be a self-defense device; we simply wish to age by stealth.

Senator Collins, your remarks on bringing, if you will, older adults into the process, absolutely required. We do that at the AgeLab, and many other researchers around the world do that as well. However, I caution those who believe that putting the consumer in the system alone will lead to innovation. Consumers do not know the power of what technology can do. They do not know the power of new design, so we have created the Age Gain Now Empathy System, AGNES, that allows my students, marketers, engineers, designers, shall we say, to feel the friction, the fatigue, and often the frustration of disability and aging, because they know how the technology can be used and are less likely to edit the fact that they feel that friction or are too embarrassed often to voice it.

On that note, yes, there are amazing technologies that are out there. Many of them are assistive, but we are also forgetting one other user. Fundamentally the consumer of an aging society are women. The future is female. The majority of them will live longer.

They are the majority of caregivers and, by the way, make the majority of household consumption decisions. If we do not frame around what she sees as a consumer, we will be confusing the user with the actual influencer and buyer, so, yes, there are many technologies out there. Your house, your toilet, your toaster, and refrigerator will be talking to each other about your nutrition. Your spoons and your forks will not just be accessible; they will be smarter. Robots will keep you company, remind you to take your meds, answer the door. One, in fact, will tell you a joke or insult you once or twice a day to keep you cognitively well. Your home will become a service platform, not necessarily just a place, and yes, I would be remiss that my own department of the Center for Transportation Logistics, the driverless car is coming, offering great promise, but I caution all of you not to be overly exuberant. Think of that first 50 feet of getting into the car and the last 50 feet of getting out of the car. Think of the system, not the technology itself.

In the spirit of Sarah Knauss, however, I ask you to think about how technology will help us work, stay engaged, and I dare say the “F” word—fun—as we think about the future of aging.

Let me close my remarks with some serious policy considerations, and, Senator Collins, you touched on a few of them.

One, affordability. How do we actually get this so that others can afford this?

Second, smart buyer. Where do I learn about these systems? How do I know which to use? And how do I get them into my life and into my home? And given that they change faster than your cell phone, how will I make sure that I stay on top of what is possible for my family?

Senator Collins, I speak to you particularly personally as a fellow New Englander. Rural accessibility. We are now looking on Capitol Hill about the discussion of infrastructure. Pavements and pipelines alone are not infrastructure. Digital access is a requirement for participation in the United States. It is no longer simply a luxury.

Last, if I can close on this: I want you to think of the longevity economy as not just a matter of policy and markets doing what is fair, doing what is nice. The fact of the matter is the fastest-growing part of the population worldwide and in the United States is the 50 and 60 plus. This is another particular to create an entirely new lifestyle, an entirely new economy, new products, services, and experiences to improve the citizens and residents of the United States, but also something that the U.S. can export.

To date, unfortunately, there is not a single place in the Federal Government where there is a podium to talk about technology, aging, and innovation on a positive note—not just about pills, not just about assistive devices, but how do we turn long life into a dividend to be cashed in to make life better?

My closing remark: Vannevar Bush was a professor at MIT, science adviser to FDR, and the dean of engineering at the time. He said that science and technology was an endless frontier. Members of the Committee, I want to put in front of you the following: that longevity and the longevity dividend, in the 30-plus years that we have gained since the year 1900 is a new frontier to use science,

technology, and commerce to chart not just how to live longer but how to live better.

Thank you, Chair Collins, Committee, and I stand by for questions and look forward to helping you in the future. Thank you.

The CHAIRMAN. Thank you very much for your excellent testimony.

Ms. McCarty.

**STATEMENT OF CARA McCARTY, DIRECTOR
CURATORIAL, COOPER HEWITT, SMITHSONIAN
DESIGN MUSEUM, NEW YORK, NEW YORK**

Ms. McCARTY. Thank you, Chairman Collins, Ranking Member Casey, and Committee members. It is an honor to share with you several examples of the beneficial ways design and technology are transforming the lives of people with physical, cognitive, and sensory disabilities. They are from two exhibits I organized—one in 2018 at Cooper Hewitt, Smithsonian Design Museum, and the other featured earlier this year at the World Economic Forum in Davos.

Senator Casey, I am delighted to inform you that in 2 weeks the exhibition opens at the Carnegie Museum of Art in Pittsburgh.

The goal of both exhibitions was to illuminate the innovative designs developed during the past decade for people with various disabilities to improve their quality of life, expanding their options and their ability to engage more fully in life.

Design plays a powerful role in shaping our lives. When applying design sensibilities to people with physical and cognitive challenges, the shortcomings of existing products and environments, as well as societal barriers and social stigmas, are magnified. Until recently, products looked clinical, perpetuating psychological barriers and how we stigmatize the user.

By addressing the needs of individuals with significant challenges, many others benefit. Curb cuts in sidewalks are a prime example whose mandated purpose and function have extended well beyond the original intended users.

I would like to illustrate a few examples of low-and high-tech solutions, several of which would have included what you showed, Senator Collins, which I included in the exhibition.

Mobility. May I have the slides, please? Thank you. Making canes stylish and objects of pride empowers the user with confidence and dignity. Today there is considerable redesigning of walking sticks. They function better. They have non-slip handles. They can illuminate at night to help prevent falls, and interchangeable handles and tips and joyous colors let the user personalize them. It means people now have choice, which will continue to expand as digital technologies are integrated into canes.

Next slide. Walkers, wheelchairs, scooters for older adults often lack elegance or grace, which stigmatizes the user. They are seen as medical equipment. Consequently, individuals often resist using them, and they do not venture outdoors, but as demonstrated by the Afari Mobility Aid, an all-terrain “walker” designed by two older adults with mobility challenges—two adults from Maine, by the way—but who want to remain active and independent, these mobility aids are both useful as well as stylish. In use, it appears like walking a bicycle .

Connecting and communication. Digital technologies—next slide, please—are undeniable game changers for many individuals with disabilities. They fill a void that is vital to maintaining a fulfilling life. Many counteract isolation, as has been noted.

A poignant example are Tobii Dynavox’s portable, eye-gazing devices that support access to communication for those not able to speak or who require hands-free communication to express themselves, their thoughts and ideas in ways and at speeds previously unimaginable. In addition to the product’s speech-generating capabilities, eye-tracking enables an individual to use their eyes as pointers to move symbols, or to type and send emails, or to edit images and films.

Daily needs of bathing, dressing, eating are essential. Next slide, please. A man with Parkinson’s disease had difficulty buttoning his shirt. His wife saw a design opportunity, not an obstacle. She was inspired by the magnetic covers of iPads and transferred that innovation to invisible magnetic buttons. It is a prime example of inclusive design. It looks like a regular shirt and can easily be marketed to individuals with limited manual dexterity.

Next slide, please. I am excited about the recent legislation de-regulating hearing aids. Everyone experiences moments of decreased hearing, a noisy restaurant, crowds of people. In earlier generations, concealing disability was a priority, but this is changing as awareness is growing, and we see people embrace their disability. These customized, low-cost, over-the-counter hearing aids are not dissimilar to eyeglasses, which were traditionally called “medical appliances” until fashion designers got a hold of them. And we see what happened. Why not glam them up?

Next slide, please. Particularly striking examples of this shift toward outward expression are these prosthetic leg covers—snap-on tattoos that are intricately patterned and available in a variety of patterns and colors. With these, the conversations turn to the appealing prosthetic rather than what happened to you. The positive reaction gives confidence to the wearer.

My last slide, how do we design transportation for everyone? In the U.S. 30 percent of individuals with disabilities have difficulties accessing transportation. Cities, streets, buses, subways, and other public spaces are not universally accessible, but as has been noted, as we plan for the future and upgrade infrastructure, we have tremendous opportunities. This Accessible Olli is a prototype autonomous shuttle bus, accessible to people with physical and cognitive disabilities, with a retractable wheelchair ramp, software that can process sign language and display other simplified information.

In conclusion, design matters. What distinguishes many of these products is that they were designed with the user at the center. By focusing on the user and designing with the user not just for the user, we cannot only understand the needs better, the product better, but we humanize design. What is needed is a mindset change. We speak about the aging population or people with disabilities as having the problem, but isn’t the real problem that many of our designs on all scales create barriers? By placing those who have been traditionally excluded central to the work of design, we not only value their ways of being, but we also reconstruct notions of inclusivity and exclusivity.

As August de los Reyes, who is quadriplegic, said, "Disability is a mismatch between my own abilities and the world around me. Disability is a design opportunity."

Thank you.

The CHAIRMAN. Thank you very much. Your slides are absolutely fascinating.

Ms. MCCARTY. Thank you.

The CHAIRMAN. Creative and encouraging. Thank you.

Ms. Gallant, welcome.

**STATEMENT OF BRENDA GALLANT, RN,
EXECUTIVE DIRECTOR, MAINE LONG-TERM
CARE OMBUDSMAN PROGRAM, AUGUSTA, MAINE**

Ms. GALLANT. Good morning, Chair Collins, Ranking Member Casey, Committee members. My name is Brenda Gallant, and I am the Maine State Long-Term Care Ombudsman. Thank you for inviting me to provide testimony regarding the essential role of assistive technology in supporting older adults and adults with disabilities to live independently in the community.

We have observed the vital importance of this technology through our work with Maine's Homeward Bound program, the CMS-funded Money Follows the Person Demonstration Program. Maine implemented this program in 2012. Since then, with the resources this program provides, 141 nursing home residents and hospital patients have been able to transition back to the community. MFP serves Medicaid beneficiaries who have been in a nursing home or hospital for at least 90 days.

In our experience, older adults and adults with disabilities want to live in their own home whenever possible. MFP assesses the needs of each participant and develops an individualized care plan to provide the services and supports needed for a successful transition back to the community. A key part of the planning includes an assistive technology assessment.

Here are some examples of how assistive technology has enabled MFP participants to gain the independence necessary to return to living in the community.

A 58-year-old woman with a diagnosis of muscular dystrophy resided in a nursing home for 17 months. She uses a motorized wheelchair, and her muscular dystrophy has impacted her ability to use her arms and affected her ability to communicate. She expressed her wish to leave the nursing home, but was discouraged by her physician, who felt that her needs could not be met in the community. However, she was determined to be in her own apartment. A critical part of her planning was access to assistive technology. An assessment recommended an eye-gaze system that enables her to use her computer with her eyes to communicate through email and have access to the Internet, as well as remote access monitoring that provides motion detectors and notifies caregivers if her routine is not followed. Additionally, a remote door entry button that she keeps with her allows her to enter and exit her home independently. Despite the initial skepticism, she has been successful in living on her own for 6 years.

A 49-year-old woman, also with a diagnosis of muscular dystrophy, resided in a nursing home for 5 years prior to her transi-

tion to her own apartment. She uses a motorized wheelchair for mobility. MFP funded a ceiling track lift to enable transfers to be done safely, requiring only one caregiver to be present; a smartphone and iPad allow her to access the camera installed outside her door so that she can see who is there and is able to operate an automatic door opener with her hand. She also utilizes an emergency response system that has GPS tracking so that when she is away from her apartment, the system will continue to operate, and she can call for help if needed.

A 94-year-old woman transitioned from a nursing home back to her own home after falling and fracturing her hip. She has macular degeneration and arthritis. MFP funded a reacher to assist in picking up, an assistive device for administering eye drops due to arthritis in her hands, an electric lift chair to help her stand and sit, and automatic door opener to allow her time to enter and exit the house safely. Additionally, she uses an Echo Plus through voice command to control ceiling fans, lights, and the thermostat. She never imagined she would be using this type of technology; however, she has embraced it and has been successful living in her own home.

MFP, and the access it provides to assistive technology, has enabled these participants to reside independently instead of in a more costly institution. MFP has enabled States to rebalance Medicaid dollars from institutions back to home and community-based services, complying with the 1999 Olmstead decision mandating States to provide individuals with disabilities the opportunity to live in the least restrictive, most integrated setting possible.

In closing, despite these successes, we are concerned that the provision of assistive technology and other services accessed through MFP is at risk. We have seen firsthand how it has transformed the lives of Maine people who have utilized its services to regain their independence. The EMPOWER Care Act, S. 548, and its companion legislation, H.R. 1342, extends funding for MFP for 5 years. We urge members of the Committee to support the EMPOWER Care Act so MFP can continue to make a dramatic difference in the lives of Maine people and thousands around the country.

Again, thank you very much for inviting me here today.

The CHAIRMAN. Thank you for your testimony. Great examples, too.

Mr. Mecca.

**STATEMENT OF ROBERT MECCA, EXECUTIVE,
LIFE AND INDEPENDENCE FOR TODAY (LIFT),
ST. MARYS, PENNSYLVANIA**

Mr. MECCA. Chairman Collins, Ranking Member Casey, and members of the Committee, thank you for inviting me to testify today. I am honored to be here on behalf of people with disabilities who need assistive technology to live the independent lifestyle that so many people take for granted. My name is Bob Mecca. I will be married for 29 years this year. My wife, Dawn, is here to support me.

I was born with spina bifida, and I use assistive technology every day to live independently, work, and be an active part of my com-

munity. I have been working in the independent living field for almost 30 years with over 20 years as executive director of Life and Independence for Today.

I use both high-tech and low-tech devices. I use a wheelchair for mobility and portable hand controls, which I have with me today. I can fit these hand controls in and out of any automatic vehicle within 5 minutes. I am currently looking for funding for an all-terrain tracked wheelchair, as I am an avid deer hunter. This outdoor wheelchair would allow me to go into the woods where I would not otherwise be able to go.

One low-tech device I use is a reacher to get things out of high places. A few years ago I had shoulder surgery, and I had to use a wheelchair and a transfer board. The transfer board was a little bit different than the normal transfer board, as it had a seat on it that slid back and forth, which made it very easy to use. I acquired the transfer board from Life and Independence for Today, LIFT's reuse program, and I got the wheelchair from the Saint Marys Pharmacy Home Health, which is a durable medical equipment provider in my home town. If I had not had access to these priceless pieces of AT, I would have been stranded in my living room looking at the same four walls for 3 to 4 months, as I only had the use of one arm. This example demonstrates that AT is not only important for people with permanent disabilities, but it is very helpful in temporary situations to keep people independent and in their own homes,

LIFT is one of 17 Centers for Independent Living in Pennsylvania. My center is located in Saint Marys. LIFT serves arguably the six most rural counties in Pennsylvania: Cameron, Clearfield, Elk, Jefferson, McKean, and Potter counties. This is an area of over 5,000 square miles, and we serve this huge geographical area with a staff of only six. We provide services to assist individuals with disabilities to live independently in the community. Currently, LIFT has 366 open consumers. We also receive hundreds of I&Rs, Information and Referral requests every year.

LIFT is a regional center for TechOWL, Pennsylvania's Assistive Technology Act program. As a State AT Act program, TechOWL and LIFT work together to ensure people with disabilities have access to and acquisition of the assistive technology and services they need to live in their communities. Under the umbrella of TechOWL, LIFT provides services through the Assistive Technology Lending Library, ATLL, which is a free service that enables all Pennsylvanians with disabilities, regardless of age or disability, to try AT devices to see what best suits them before they buy something. LIFT also facilitates the Telecommunications Device Distribution Program, TDDP, for our six counties. The TDDP provides telecommunication devices to qualified applicants with disabilities. These devices allow individuals to use telephones independently. LIFT also has an assistive technology reuse program. We take donations of lightly used equipment and recycle them to those with disabilities who would otherwise not have the means of obtaining them.

As executive director of Life and Independence for Today, I serve on the board of directors of the statewide Independent Living Council, which is a Governor-appointed position. I also serve on the

board of the Pennsylvania Council on Independent Living, PCIL, which is a membership association of Centers for Independent Living in Pennsylvania. I travel quite a bit for my job, and when I need overnight accommodations, I always try to arrange for wheelchair access. For someone with a mobility disability who is active like myself, things like an accessible shower, shower chairs, and grab bars are essential to my independence outside of my home.

In closing, I would just again like to say thank you for allowing me to represent people with disabilities who use assistive technology to ensure their independence and become and remain productive citizens in their communities. I would be happy to answer any questions. Thank you.

The CHAIRMAN. Thank you very much, Mr. Mecca.

Ms. Gallant, could you describe in a little more detail the process that you use to assess what kinds of technology would be useful to an individual who looks to be a promising candidate for transitioning from a long-term-care facility back to their own home? I am going to ask you to turn on your mic.

Ms. GALLANT. I am sorry. Any individual that would be transitioning would have an assistive technology assessment performed, and based on that assessment, the individual would be visited, for example, if they are in a nursing home or a hospital, so the assessment would begin in the setting that they are in, and then also include looking at the home that they are going to move into, and really look at the medical needs and the functional capabilities of the individual to develop a very individualized plan, and then the individual would be given training and support with respect to how to use the technology and then ongoing support for any questions or concerns, and there would be followup, so it is a very individualized and specific assessment for each individual.

The CHAIRMAN. Thank you.

Ms. McCarty, as I was listening to that explanation, I wondered whether it was a hard sell to get seniors to be open to the new technology. When you had your exhibit, what was the reaction of people who looked at the wonderful products that you displayed in your slides?

Ms. MCCARTY. I would say euphoria, and we just had crowds of people coming to the galleries, people of all ages, all abilities, many expertise, and we had people coming looking out of curiosity. We had people coming to look what they might be able to get for themselves. We had people looking for friends or family members. We had doctors. One day I was giving a tour, and this man latched onto the tour, and he finally came around a pedestal and confronted me, and he just said—he interrupted the tour, and he said, “Can I just say something? This is the best exhibition I have ever seen. I see many exhibitions, and I am a doctor. Why don’t I know about these products?” That was what so many people said, and it really staggered me. In this day of the Internet, how many people who could benefit from these products do not know about them? How do we get the information out? Many people do not even know where to look? They do not even know that something like this exists.

We have a real education problem from the beginning, and I would say that even a lot of occupational and physical therapists,

you know, are maybe not imparting some of that information, so really, I am thrilled that the exhibition is traveling, and hopefully that will help highlight some of these wonderful products and thinking.

The CHAIRMAN. Maine is the oldest State in the Nation by median age, so just as soon as you get done in Pennsylvania, I think you should bring your exhibit——

Ms. MCCARTY. Give me a place, we are there. Thank you.

The CHAIRMAN. I do think you raise a really important point, that the average person is not at all aware, but even the medical profession often does not know about it.

Dr. Coughlin, I see you nodding in agreement with that. You raised a really important point about when we think of infrastructure, we have got to think of access to the Internet, broadband, transmission speeds, all of those issues—cellular service. That is an issue in a lot of rural America, including some parts of rural Maine, so up front, many of these technologies, particularly those that require Internet capability, may still be cost-prohibitive for many families, and it is ironic because it actually saves so much money over institutionalized care, which in some cases, if it is rehabilitative care, Medicare may be paying, or if it is long-term care, Medicaid is frequently the payer, so we have a sort of penny-wise, pound-foolish approach to this issue.

Are there alternatives available at different price points that would at least make some of these technologies available to individuals and improve their quality of life?

Dr. COUGHLIN. Yes, Senator. As I provide in greater detail in my written testimony, one of the greatest challenges we have is a coming technology inequality gap around affordability, let alone accessibility, particularly in rural America. The affordability issue, there are two ways to look at this, at least. The first one is that, yes, it is expensive, but they are getting cheaper over time. Many of these devices are coming down in price, and over time, many technologies, like a computer, flat-screen TVs, and the like, we have seen them markedly drop, so that is the good news. The trouble is we need to support people in the here and now.

The research that we are doing is suggesting that part of the price problem is we are designing technologies for a specific market segment, which means market failure. We need to design technologies that everyone wants, that is cool, convenient, and provides care. That way we get full market capability, and by the way, then people want to buy it. We create a whole new market. The notion that we are pursuing in Massachusetts is creating a whole new business around longevity economy clusters to develop, manufacture, and export these technologies, not just to people in Massachusetts but around the world, so we get economies of scale, so yes, while there should be Government support, agenda setting, I think there are design, policy, and market forces that we can bring it down and make it accessible to all.

The CHAIRMAN. Very exciting.

Senator CASEY. Thank you, Chairman Collins.

I will start with Bob Mecca. In your testimony you discussed the work you do leading LIFT to provide assistive technology to very large and very rural communities in our State, and you mentioned

those six counties alone are 5,000 square miles, so that is a lot of territory and I am sure on a limited budget. The bill that Senator Collins and I will introduce will authorize more funding to support your work and the work of others.

Here is my question: As someone who provides assistive technology in that rural part of our State, can you tell us about how the assistive technology needs of older adults with disabilities creates a challenge and how additional resources can help you serve such a rural area?

Mr. MECCA. Yes. First of all, serving older adults with disabilities has its own challenges because we often run into—they may call us for assistance or they need a certain device to help them or they want to look at different devices, and, you know, when we ask them, OK, what is your disability, “Oh, I do not have a disability. I am just old, and I cannot do things like I used to.” So that is a challenge in itself, getting them to identify themselves as a person with a disability, and then once we get them to see, you know, what a difference adaptive equipment or assistive technology makes, it makes a world of difference, and they just are so thankful that we can provide something to help them, say a bill reader for someone with a visual disability that can tell them what denomination their dollar bills are. That is so helpful to a person to get out into the community and pay for items. Then they know what they are giving the person at the other end of the register.

Also, I wanted to point out that it is over 5,000 square miles that we cover, and with a staff of six, and how we do that is we go to our consumers directly. We do not have them come to us, because although we have been blessed to have the same transportation provider cover the same six counties that we cover, unfortunately there are not routes that go between towns and so forth, so that makes it way too expensive for people with disabilities of any age to come to us, and so we have to go to them, and as you said, it is on a very limited budget, so any additional funding there would just be a godsend for us to help so many people that we have in our area with disabilities and older Pennsylvanians.

Senator CASEY. Well, thanks for that answer, and I also wanted to followup on the nature of the technology. We have heard a lot today, and Senator Collins did a great job of explaining some of the devices we have now, some rather simple but helpful, but some very complex and also very helpful as well.

It seems that, like anything in life, the more complicated the technology, the more expensive it is and, therefore, sometimes difficult to obtain. Certainly one of the examples of that might be alternative speaking devices, which we have learned so much about, which can restore the ability of an individual to communicate with the world around them. I am going to be introducing a bill to increase access to those kinds of devices.

Bob, can you share with the Committee specifically why accessing this type of technology is both so challenging but also to share how targeted resources might help those individuals?

Mr. MECCA. Well, augmentative communication devices that help people, you know, with speech disabilities are definitely one of the more advanced technologies. They can be. They can be as simple as a person one time that I know had a glass board with numbers

and letters on it, and they would look at each number and spell everything out slowly, to the advanced communication boards that are very technical and they need to set them up oftentimes in advance to say a sentence or whatever, so they are a lot more expensive. The more technical they are, the more expensive they are.

Also, at LIFT we used to have a program that we called "Within Your Reach," and what we did was we partnered with at least one library in each of our six counties, and we put assistive devices in the library in a prominent place where people could go in there and look at them and use them, and then if they wanted more information on it, we left our information there, and the library staff were trained to contact us, and then we set up appointments for people to help them. That was like a one-time funding thing, so we no longer have the funding to do that, although we still have the equipment at the libraries. It is outdated now because that was probably about 5 years ago, so the equipment is outdated now, but it still provides people that go in there with the ability to look at that equipment and say, "I could use something like this," and then they contact us, and we can provide them with the newer equipment, so we still have a lot of equipment out at the libraries, although it is outdated, and getting funding for something like that or for adaptive equipment or services to adaptive equipment would be a godsend to people, especially in rural areas like my service area, because we call that program "Within Your Reach" because people in very rural areas like that did not have the access that people in large cities have to different types of adaptive equipment, and we put that equipment in their back yards essentially, and they were able to look at that in the libraries in their own communities. That is priceless.

Senator CASEY. Bob, thank you.

The CHAIRMAN. Senator Rosen.

Senator ROSEN. Thank you. Well, thank you so much for bringing this. Unfortunately, none of us is getting any younger. I think there is no glasses—there is no print that is too big for me anymore, but seriously, I took care of my parents and in-laws as they aged, so I have been through rehab and assisted living and all those kinds of things with my parents and my in-laws.

Myself, I recently broke my wrist and had some challenges, although they are temporary. My husband had back surgery, so people do have all kinds of challenges, and as I sit here and listen to you, the things that I really think of are two really exciting areas that we could build our economy, build our job force. I said I see a "Better Living Through Technology" store chain out there somewhere that would be a place—you know, you see "As Seen on TV," or some of those, that would be a great business venture. Anyone out there listening to these hearings, I would think this would be something terrific.

The other thing that I really see—and we talk a lot about the people pipeline, and we talk about creating jobs, and so you think about all the things—not just that engineers do and designers, but we think about our physical therapists or occupational therapists and the people who work in not just senior facilities, assisted living, or in the care industry, but there are real places, I believe, that we could probably help fund and create certifications so then

perhaps through Medicare and Medicaid there would be reimbursements for people to go into these types of fields that will help us all.

How do you think you might see us adding some kinds of certifications perhaps, apprenticeships, ways that we can boost the people working in this area so they have a career that they would get paid from to do this kind of work that we are going to need for so many people?

Dr. COUGHLIN. Senator Rosen, excellent thoughts and remarks. One of the challenges I think you will find in the education field is that while the technology, such as the smart technologies in the home for medicine, education, and the like, are advancing greatly, a study that we did in the lab showed that there was very few professionals being trained on actually how to use these technologies, so I would suggest that certification is not just a way to get people in the pipeline. Actually, most of the practitioners out there providing care do not know how to use the very systems that actually exist out there to improve our lives.

Senator ROSEN. Do you have a suggestion how we could maybe help our community colleges or what kind of vehicle could we use to train either people who are looking for new careers or our young kids wanting to go into a new career? What would you suggest that we could try to promote or discuss here from our bully pulpit?

Dr. COUGHLIN. Just very quickly, and I will yield to my colleague here. Two things. One is to put it, as you do best, put it on their agenda. Perhaps funding is one of the things you can do, but more importantly I think is to actually highlight aging and life tomorrow as a positive issue. A good number of us have glasses. We are sitting here talking about special technologies, but these are the original assistive technology.

Senator ROSEN. Right.

Dr. COUGHLIN. I put an Italian guy's name on the side, and suddenly everybody wants to buy these, sell them, and everything else. They are no longer that special thing. I think getting the idea that this is a new entire way of living that is exciting will get young students to want to commit to a profession that engages all of us in life tomorrow.

Ms. MCCARTY. I think that is an excellent question. I am so glad you asked it because I think about this all of the time.

First of all, I just want to say that I think there are a lot of young people today who are very interested in social impact design. The museum collaborates with a lot of design schools, and 30 years ago, when I did my first exhibition on the topic called "Designs for Independent Living," it was difficult to find young people interested in this or even design schools. Today Cooper Hewitt has partnered with a number of schools and students doing prototype products. We included some of them in the exhibition, and they said that this has really impacted what they want to do in their career going forward, so I think the time is right. There are a lot of young people just interested in wanting to make a difference in the world today, unlike I have seen before during my life.

Second of all, I am a caregiver myself, and I think about this all the time. I have spent several months when my partner was going through rehab, and my eyes, of course, were looking at everything

and all the equipment. I asked a lot of questions of the therapist to train me so that when we went home, I would know how to lift him and do other daily tasks just helping him dress, et cetera, and that is not something that most people who are trained in, like a family member, somebody who gets a disability or somebody is discharged from a hospital, they are cared for in the hospital. Everybody is—there are high emotions just tending to the person. They do not know the questions to even ask when they go home.

Senator ROSEN. Would you say expanding this in the home health care certification—

Ms. MCCARTY. I think the opportunity is enormous for jobs, and I am not talking high-level education jobs. It is really—

Senator ROSEN. That is what I mean, at the certification community college level.

Ms. MCCARTY. Exactly, and I think the opportunities are immense, and I could just rattle off one example after the next, but it is really about learning how to just take care of people, their daily needs, so I know this is talking about a lot of high technology. There are a lot of low-technology things—

Senator ROSEN. Perhaps you might share those with us—

Ms. MCCARTY [continuing]. that are very important.

Senator ROSEN [continuing]. when we talk about education and people pipeline, these might be some of the things we can take back to our community colleges and find ways that we can fund things or certify or ways that we partner a career with getting paid for that career, right? That is important.

Ms. MCCARTY. Right. You know, we are doing a lot, we are paying a lot. We are doing a lot of medical research to keep people living longer, but that is just going to bring even more disabilities the longer people remain alive, so it is a big audience that we could really address.

Senator ROSEN. Thank you so much.

The CHAIRMAN. Thank you.

I am going to followup on the question that Senator Rosen just raised and direct it to Brenda, and that is talking about the challenges that you face and what the biggest challenge is as you try to do all of this planning.

I know from talking with home health agencies in Maine that they feel stretched very thin, that there is a shortage of home health workers, and I would think that, in addition to the technology, that may be an important element as well. What is your experience about the biggest challenges?

Ms. GALLANT. Okay. Really, the biggest challenge is initially finding—

The CHAIRMAN. I am sorry. I do not think your mic is on.

Ms. GALLANT. Yes, so what we are finding is finding affordable, accessible housing across the State is a real challenge. Additionally, as you said, the direct care worker shortage also makes it a challenge to be able to arrange home care services, which are so critical in terms of the planning. However, with the team that we have brought together, we are able to find housing. Usually 3 to 6 months is about the average time. We do have a housing coordinator through Alpha One, Maine's Center for Independent Living, that works on the housing, so really the team comes together to

overcome these barriers, and it takes time, but we really can—as you can see, the assistive technology is such a critical part of this and really can supplement in terms of staffing, the remote monitoring can really help in terms of reducing the need for staffing, so it is really the team approach and being diligent in overcoming these barriers, and we found that we can—it may take some time.

The CHAIRMAN. Thank you.

Dr. Coughlin, let me pick up on a point that was just made about remote sensors. Obviously, this technology has the potential not only to allow individuals to live fuller lives and stay in their own homes, but in some cases, it may raise some privacy issues, and I would be interested in hearing your comments since you involve seniors on whether or not they are concerned about having sensors that monitor whether they open the refrigerator and thus are eating, for example, or cameras that can see them. Is that an issue that comes up? Or do people think the tradeoff is worth it?

Dr. COUGHLIN. There is certainly an issue that comes up because think about the fact that it is not just your sensors in the house knowing that you are walking to your refrigerator. It is also your toilet talking about you as well. Input-output model is the best way to describe whether you are taking your medications, you are eating well, whatever, you know, the like.

However, older adults tend to have, believe it or not, greater levels of trust than younger people in the institutions that might be so-called watching them, so yes, Senator, we have to balance dignity with independence, but one of the challenges that we see that older adults seem to be willing to do, which is I will give you some of my privacy if you give me some independence and safety.

I will give you an analogy that many of us can identify with. How many of us can say we have a credit card in our pocket? We now know your price for privacy. My American Express probably knows more about me than my wife of 30-odd years.

The CHAIRMAN. Well, anyone who goes online and does a search and then gets all those ads realizes—

Dr. COUGHLIN. Yes, that is somewhere between cool and creepy.

The CHAIRMAN. Yes, exactly. I think it tends toward creepy myself, but thank you. That is really very interesting.

Ms. McCarty, did you want to add anything to that? Were those issues raised when you did your exhibits?

Ms. MCCARTY. They were raised, and I got very similar reactions. Most people were very—the tradeoffs slanted more toward wanting the technology, but I know that it is definitely something that will be an issue and something that needs to be discussed.

One of the products that we featured in the exhibit that required remote monitoring was pill taking and pill bottles with chips in them so that maybe a caregiver from afar could really monitor if somebody took their pills or not, which it is a real issue, you know, people not taking pills, but I mean, it is a real reason why many people are not getting better because they are not taking their pills for various reasons, so there are tradeoffs, but just like in the rest of society, we need to just keep talking about this.

The CHAIRMAN. I should probably clarify my “creepy” comment. When I was talking about that, I was talking about the fact that when you are doing a search for a particular item on the Internet,

you all of a sudden get all these unsolicited ads because your data is being sold or distributed. It seems to me that is very different from sensors that are helping you be independent, healthier, and live in your own home. I think there is a big distinction.

Dr. COUGHLIN. If I may briefly, Senator.

The CHAIRMAN. Yes.

Dr. COUGHLIN. One of the other reasons we saw that the technology was accepted by older adults despite privacy concerns, if you can design systems that not only remind you to take your meds or to eat well on the more, shall we say, lower end of Maslow's pyramid, but also encourage a connection with family and friends, so yes, did you take your meds? And oh, by the way, Mom what was that recipe you used to use for cookies? So you can use a technology to engage people and reduce social isolation, and for that they are willing to tradeoff a little bit of privacy.

The CHAIRMAN. Very good point. Thank you all.

Senator CASEY. Thanks very much, Chairman Collins.

I will start with Ms. McCarty because you gave Pittsburgh and Pennsylvania such good publicity here, but I really open it up to the whole panel. The opportunity that we have when we are updating a law, sometimes every 5 years but sometimes a lot longer, like the Assistive Technology Act, in this case 15 years, to give you a chance to, as you have already in one way or another, but to reiterate maybe in more of lightning round to say I hope you do the following when you are making changes to that act.

I guess the basic question is how should we who are putting together legislation use this opportunity to update the act and make sure it is capable of making new technologies accessible for those who can benefit from them. Ms. McCarty, we will start with you, and anyone else who wants to add your 2 cents.

Ms. MCCARTY. Well, I think that what is really important in this is that it be affordable, as has been mentioned, and the good thing, as we all know, is that a lot of our technology has been coming down in price. In fact, I think one could buy some of these devices for what it takes a family to buy groceries for a month. I mean, it is really quite staggering that it is so—it is mind-boggling what is in reach with us and what we can do with the technology.

The other thing is: How do we get the information out that I mentioned earlier? That was something that just kept being reiterated over and over again, and I think that we can continue to be looking for positive ways to utilize the technology and to really listen to the users. That is where we are getting some of our best and most important information, is what the users need, and as I mentioned the example of the curb cut, a lot of these improvements that we can be making, if we use people with more challenging needs or complex needs and look at their needs and try to solve those, we are actually going to be solving a lot more needs of a lot more people, and I think that is the goal to really be striving for, is not just always looking at a targeted group of people. We are all going to age. We all get a disability at some point in our life, and rather than separating this group of people from this group, if we look at everybody together, but the more complex needs, I think that we are going to be much more inclusive rather than exclusive in what we are doing.

Senator CASEY. Thank you. Anyone else?

Dr. COUGHLIN. I would chime in as well, Senator. I think accessibility is absolutely important. To pick up on accessibility, rural digital infrastructure, again, it should be part of the larger dialog here on the Hill with respect to infrastructure. We need to get these things into retail. This is where solutions are found by shoppers and by families and the like, so having a website that no one knows about, we need to solve what we say in Government is the smart buyer problem. Where is it? How is it? How much does it cost? Should I buy this one versus another?

Also, I hear a lot about users. I want to introduce a whole larger discussion on influencers and buyers. Going back to the discussion, the future is female. The family caregiver, one in four American families provide upwards of 26 to 29 hours of care per week to an older adult out there. She is the one choosing. She is the one buying. She is the one making the tradeoff between life, work, job, career, and the like.

Then last, if I may, I think that the bill that you are thinking of sounds like a great opportunity to also aim high. This is not about more older people requiring more of what we know about old age. This is an opportunity to have the Federal Government put a stake in the ground to say longevity is an opportunity to aim higher, to live longer, better. It is a market. It is a policy. It is a new vision of an older but still innovative America.

Senator CASEY. Thank you. Bob?

Mr. MECCA. If I could say something as well, every State has an assistive technology program through the AT Act, and if you—you were asking what could be added into the new bill. I think a really good way is to—LIFT, Life and Independence for Today, as a Center for Independent Living, we are an assistive technology resource center for TechOWL, and there are several in Pennsylvania and I am sure across the United States. Every State has several ATRCs, we call them, and if you go to them and, you know, maybe they could talk with their consumers and see what people actually—what the need is out there, and what improvements they think could be used, that would be a very good outlet for you to, you know, see what is needed for the new bill.

Also, Centers for Independent Living also serve people with disabilities of all ages, and you could go to each Center for Independent Living in general and ask that, you know, they go to their consumers with mobility disabilities or assistive technology needs and, you know, see what their thoughts are on getting what type of devices they need and so forth.

Senator CASEY. Bob, thank you.

He gave me an opportunity to very proudly promote my State again. Now, what Bob is referring to is TechOWL, the Temple mascot, Technology for Our Lives, and you cannot see it from a distance, but all these categories, lending library, free special phones, used equipment exchange, information and assistance, emergency plans, so folks can go to TechOWL.pa.org for that, but it is really interesting what they are doing, and Bob works with them. Temple being in Philadelphia, you are hours away from them, but they have got a statewide presence.

Ms. Gallant, I do not know if there is anything you wanted to add.

Ms. GALLANT. I would agree that I think it would be excellent to make sure that the Area Agencies on Aging and the Aging and Disability Resource Centers have the resources to provide information to older people about technology and perhaps funding to provide that, as well as Maine's Centers for Independent Living. I think that is a really important way to get the word out to people.

Also, I just want to make sure that people that are in nursing homes and hospitals for extended periods of time have access to technology because we have shown that they can live independently through the Homeward Bound program. It saves money. The health outcomes are improved. Quality of life is improved. We have seen people come out of nursing homes after 15 years, and actually the 141 people that we have served, the average length of stay in a facility was 2 years. However, we have had some younger people, 15 years, who went out into the community, and the people I have described that you would not think could be in the community but for the technology, along with the other supports, so to make sure the funding is there to provide the technology to make this possible, because people do want to be independent.

Senator CASEY. Thank you.

The CHAIRMAN. Ms. McCarty?

Ms. MCCARTY. Thank you. One more thing I would like to add, because it is something that I hear over and over again from designers, is that what can we do to incentivize manufacturers to take this on and produce these products and work with designers and people to really bring—to produce some—so many designers recount stories of working on a product, and it is all tooled up, ready to hit the button to be mass produced, and then suddenly the brakes are put on for various reasons, and I have heard that over and over again, where a product goes into production, has a very, very short life, even though it is a really good one, and I think that would be really important if we could find ways to incentivize manufacturers.

A store like Target, just 2 years ago we featured one of their adaptive clothing items in the exhibition, and Target, which really is—their products are affordable to many, many people, they have now a line of adaptive clothing that just continues to sell out immediately for mostly children at this moment, children with various types of disabilities, but they are showing that it really does work.

The CHAIRMAN. Thank you very much for adding that.

Ms. Gallant, I am so glad that you told us of the example of someone who had been in the nursing home for 15 years and was able to transition due to the excellent planning that your office did and the use of assistive technology. That is just so encouraging, and your 2-year average is also impressive because I must say that when I first learned about your program, I assumed it was people who were in for less than a year, for short stays, so that is so encouraging and really underscores the value of the work that you are doing, so congratulations for that.

I want to thank all of our witnesses for traveling to Washington today and increasing our understanding of how technology is improving the lives of older Americans and those with disabilities.

For me, the bottom line is accommodating people's preferences and allowing them to live fuller lives, and in most cases that means staying in the privacy, security, and comfort of their own home, and I am excited by what I have learned today, by the array of technology, but I have to say if a lot of this is new to those of us who serve on the Special Committee on Aging, I cannot imagine that many of our constituents realize what is out there, and that is why I think that the work that is being done at the State level and by Mr. Mecca's group as well as in the great State of Maine is so important, but so is the technology development at MIT, the vision of an economy where we embrace those who are growing older and improve their lives and look at the job implications of this that Dr. Coughlin met and, Ms. McCarty, your exhibition cannot be understated how valuable that is for people to see it.

At the risk of telling a personal story, but since Senator Rosen did, I am going to follow. A couple of years ago, I very badly broke an ankle and had to have surgery, and I have eight screws and a plate in it, and when they told me they wanted me to use a walker and I looked at the walker, I would only use it inside the house because it was—if I had one of those cool walkers that ironically are developed by the University of Maine, I would not have felt nearly as self-conscious, and when I came back—I used a cane way before I was supposed to because I just wanted to get rid of that walker.

Seeing the design options now are so exciting and embracing it and making the prosthetic limbs almost a fashion statement is—it is really exciting and I think really makes a difference to people.

As someone who cosponsored the bill to provide over-the-counter access to hearing aids, I was very excited to see the fact that you are embracing the hearing aid and using it as a fashion statement. That was just so fascinating to me.

I very much look forward to working with Senator Casey on the 21st Century Assistive Technology Act and to reauthorizing the EMPOWER Act that has been mentioned as well. We want to make sure that these technologies reach older Americans and those with disabilities.

Before I turn to Senator Casey for his closing comments, I want to pick up on something that Dr. Coughlin said, and that is the fact that we lack in the Federal Government a central place that can focus on these technologies in a more comprehensive way, and that is something I would be very interested in working further with you on, and perhaps we could include that in the legislation that we are introducing and that you have been the lead on. I think that would really help as well.

Dr. COUGHLIN. We would be delighted to help. Thank you.

The CHAIRMAN. Thank you.

Senator CASEY. Thank you, Chairman Collins.

I want to thank the Chairman for holding this hearing on assistive technology. I obviously want to thank our witnesses for being here, for your testimony, and for the effort you made to be here with us and to provide your expertise, experience, and insight. You have provided us with important examples about how older adults, people with disabilities, and their caregivers can benefit from a variety of assistive technologies, and also how high-and low-tech solu-

tions can be used to enable people to remain independent and socially connected to their families and their communities, especially in rural areas of our State and our country.

I also want to thank the folks in the back who are from this region, from Maryland, the District, and Virginia, for bringing assistive technology not only here to the Capitol but here in this hearing room so that we could see this technology and see it up close.

I look forward to working with Chairman Collins and other colleagues in the Senate to make sure that this technology gets into the hands of those who need it.

I was struck by so much of the testimony today, but I wanted to point out one line from Bob Mecca's testimony. He said at the top of page 2, quoting where he was at this point in his life, he said, "If I had not had access to these priceless pieces of [assistive technology], I would have been stranded in my living room looking at the same four walls for 3 to 4 months, as I only had the use of one arm."

Many people in our families and our communities throughout our Nation are often imprisoned by a disability or in some cases more than one disability. Assistive technology unlocks them from that prison, and we have got to do everything we can as we learn about this technology, as we expand the universe of ideas, to make sure that as we are working on legislation that we keep in mind those individuals who can be very much isolated without that technology.

Chairman Collins, thanks for having the hearing, and we are looking forward to working with—or continuing to work with you on these issues.

The CHAIRMAN. Thank you very much, Senator Casey.

Members of the Committee will have until Friday, May 31st, to submit additional questions for the record. If we get any, we will send them your way.

Once again, I want to thank each of our witnesses for being here today. You really were terrific in enhancing our understanding, and I also want to thank our staff for their hard work and insights.

Thank you very much, and this hearing is now adjourned.

[Whereupon, at 11:02 a.m., the Committee was adjourned.]

APPENDIX

Prepared Witness Statements



WRITTEN TESTIMONY OF

JOSEPH F. COUGHLIN, PhD
DIRECTOR
AGELAB
MASSACHUSETTS INSTITUTE OF TECHNOLOGY

BEFORE THE
SPECIAL COMMITTEE ON AGING

UNITED STATES SENATE

*AGING AND DISABILITY IN THE 21ST CENTURY:
HOW TECHNOLOGY CAN HELP MAINTAIN HEALTH AND QUALITY OF LIFE*

MAY 22, 2019

Massachusetts Institute of Technology
AgeLab
77 Massachusetts Avenue, E40-275
Cambridge, Massachusetts



Statement to the US Senate Special Committee on Aging

Joseph F. Coughlin, Director, Massachusetts Institute of Technology AgeLab

May 22, 2019

Thank you, Chair Collins, Ranking Member Casey and Committee Members for the opportunity to discuss the challenges and promises of technology-enabled innovation to improve the lives of older people and their families. My remarks are informed by the extraordinary research of my MIT AgeLab colleagues, students and countless collaborators I have had the privilege to work with worldwide – any incompleteness, or errors, are entirely my own.

Massachusetts Institute of Technology AgeLab (agelab.mit.edu)

In 1900, life expectancy for much of United States was under 50 years old. Today, living well into one's 70s, 80s and beyond can be expected. Perhaps the greatest achievement of humankind is longer life. We must now build a society that can fully exploit our 30-plus year longevity bonus. Longevity, however, requires new thinking.

The MIT AgeLab is funded by businesses and NGOs worldwide to invent new ideas and to creatively translate technologies into practical solutions that improve the quality of life of older adults and those that care for them. Equal to the need for novel ideas and new technologies is the belief that innovations in how products are designed, services are delivered, or policies are implemented are of critical importance to improving quality of life.

The MIT AgeLab works in interdisciplinary research teams drawing upon expertise in engineering, the social and behavioral sciences, as well as design, marketing, and medicine to address challenges in transportation and community development, health and caregiving, housing, retirement, and the workplace.

Today, I would like to address seven issues in my remarks today:

1. Our Current Old Age Story
2. Technology Industry Bias & User Stigma
3. Users, Women & Transcendent Design
4. A New Vision of Old Age & Technology
5. Technological Inequality & Rural Access to Digital Infrastructure
6. Bridging the Nation's Aging & Technology Gap
7. Regional Longevity Economy Clusters: Aging As Competitive Advantage

Our Current Narrative of Old Age

The oldest and most powerful technology is the story. Stories, or narratives, help us make sense of the world. Our narratives explain cause and effect, why something is important while other things are not. Stories also define in, and out, the range of the possible.

As I observe in my book, *The Longevity Economy: Unlocking The World's Fastest-Growing, Most Misunderstood Market*, our current story of old age is, in fact, made up.¹ What objectively should be viewed as an amazing achievement, old age, is most often referred to around the world as everything from a virtual “gray dawn” that portends a coming apocalypse for national pension and health systems to the planet’s “ticking time bomb”. Instead of celebrating longevity, the story of old age has made older people problems to be solved rather than a societal victory and opportunity.²

Old age, as we know it today, has not always existed. Older adults, elders, or seniors were an important and productive part of society even in ancient history. However, in the 1800s the British medical community developed the theory of vital energy. The theory explained that a person was born with a limited amount of vital energy. And, over time – or if expended on what the Victorian era deemed as less than appropriate behaviors – a person’s energy would simply be depleted. “Old” was simply what happens when you run out of vital energy, explaining everything from certain poor behaviors or mental states, to explaining why a younger person is more likely than an older person to survive a serious illness. Old age was no longer something to be revered, or a source of wisdom, but instead was redefined as a half empty container of lost vitality. This story of old has resonated through the decades and is reflected in our language and institutions, e.g., to be old is to be over the hill, tired, requiring one to *retire*.

Technology Industry Bias & User Stigma

Stories of lost vital energy still have an impact today. The very institution of retirement keeps many older adults out of the workforce and the technology innovation value chain.

According to a 2014-15 PayScale study of technology companies, only 3 of the top 18 firms reported a median age of workers over 36 years old, while the nation’s median workforce age is over 42. However, the tech sector reflects more than an age imbalance; some technology industry icons reflect a distinct bias.

¹ Joseph F. Coughlin, *The Longevity Economy: Unlocking the World's Fastest-Growing, Most Misunderstood Market*. New York: Public Affairs (2017).

² See, for example, Peter Peterson's book, *Gray Dawn: How the Coming Age Wave Will Transform America – and the World*. New York: Three Rivers Press (2000).

Facebook founder Mark Zuckerberg has been quoted saying that “Young people are simply smarter.”³

Without many older workers providing insight into how technology can be developed to improve the lives of all people, regardless of age, however, many technology firms are left defining old age around stories and myths that are simply accepted as fact. These stories include:

*Older adults don't like technology;
Older people simply don't understand or even able to learn anything new;
or,
Older adults spend their entire day managing their health.*

Because older consumers are rarely part of the design process, these stories influence the thinking of even the most well intentioned technology researchers, developers and marketers. Some developers rely on personal points of reference (typically an older loved one) or on a handful of interviews. The result of this flawed process is often products with maladroitness and an absence of style. Devices with font type too small to see. A crowded field of small multicolor buttons frustrating nearly every user – except perhaps for the young designers/engineers themselves. And, in keeping with the myth that older users’ lives revolve solely around health problems, an abundance of applications to monitor bodily functions and medication use.

The dominant story of old age, combined with the dearth of older users integrated into the technology innovation value chain, has resulted in most products developed for older people to be big, beige and boring.⁴ Even products developed applying the principles of universal design are often packaged in medical blue plastic, more at home on an emergency room crash cart than on a family room table.

What Does a Product Say about You? Technology, Aging & Stigma

A secondary effect of big, beige and boring devices is that they often stigmatize the user. Products are as much about what they do for the user as what they communicate about the user. Personal emergency response services, or PERS, for example, are profoundly rational, and for many, a lifesaving necessity. These wireless systems allow the user to call for help by pressing a button on a pendant or bracelet. Unfortunately, many of these devices also symbolize the frailty of the user.

³ See *Fortune Magazine*, “Tech Industry Job Ads: Older Workers Need Not Apply,” July 19, 2014, <http://fortune.com/2014/06/19/tech-job-ads-discrimination/>

⁴ Joseph F. Coughlin & Luke Yoquinto “Technology for Older People Doesn’t Have to be Ugly,” *Wall Street Journal*, October 14, 2018 <https://www.wsj.com/articles/technology-for-older-people-doesnt-have-to-be-ugly-1539546423>

PERS have exceedingly low adoption rates by the very people who need them. Of the 65-plus year old frail population, adoption rates of PERS systems remain in the single digits. Even in nations where the services are partially, or fully, subsidized by government, adoption rates are below 20 percent. Users who do have a PERS system report that they often leave the device on a table in another room while they shower, use the bathroom, or are occupied elsewhere in their home. According to a 2009 Pew poll, only 35 percent of Americans over 75 reported feeling “old.” But 100 percent of people know that PERS, and other big, beige and boring products, are for *old people*.⁵

However, there is cause for optimism. Slow progress is being made. Advances in artificial intelligence and devices, such as smart speakers, e.g., Amazon Echo, Google Home, that enable users to control many home functions by voice commands, are making interfaces ageless. The explosion of wireless earbuds and earphones, worn by people of every age, are making it possible to age and manage hearing loss without stigma and, effectively, to age by stealth.

Users, Women & Transcendent Design

Technology developers and marketers must not only understand older consumers' needs and wants, they must strive to exceed them. That is, rather than simply developing technologies to assist with basic tasks, they should envision entirely new lifestyles. Products and services must transcend simple functionality, basic usability, and innocuous form, and seek to excite and delight users. When was the last time any developer started with the premise of *thrilling* the older user? Engaging users and applying radical empathy in the design process can advance this heady goal.

Understanding who the user is may not be as clear as it appears. There is greater health, disability, economic, educational, cultural, and geographic diversity among older Americans than nearly any other age cohort. Moreover, what is old was defined by political consensus, not biology or the laws of physics. It is unclear to many developers what an older consumer is – for most people oldness is typically 15-20 years older than their current age. For the very young tech industry, at Amazon, for example, where the average employee is 31 years old, old age might start at 46 or 50 years old.

The Future Is Female

While the focus on the older user is necessary, it is critical to understand who may be the key influencer. In most cases, this is a woman. As I note in my book *The Longevity Economy*, the “future is female.” She is not only likely to live longer, she is also most likely to be the primary caregiver of an older adult. In fact, the oldest adult daughter, particularly if she has a partner without a sister, is likely to have far more parents to care for than children. Women, predominantly

⁵ See Coughlin, *The Longevity Economy* (2017) pg. 73-75.

middle-aged women, are also the principal buyers of healthcare products, consumer goods, home improvement supplies and other related products and services. She effectively serves as the chief consumer officer and gatekeeper of any product or service to be used in her older loved one's life. While certainly not fair, aging and caregiving are disproportionately a woman's issue, and she, along with the older user, must be integrated into the technology design and development process.

Many research and innovation centers around the world are successfully integrating the user in the design process. Surveys, ethnographic studies and focus groups are common methods, but some groups are going beyond these approaches. For example, the MIT AgeLab manages consumer panels with older adults and caregivers from around the world. One panel is the AgeLab's 85-plus Lifestyle Leaders, which provides unique insights from the oldest old regarding product and service design. AARP's Hatchery offers a platform to startups not only to learn from AARP's wealth of institutional knowledge, but also to learn from older users directly. San Francisco-based Aging 2.0 also matches startups with older users to ensure that there is a fit between the would-be consumer and the product idea. Leading Age, the voice of the non-profit senior housing industry, manages the Center for Aging Services & Technology, which connects technology companies with senior housing operators and residents.

While it is necessary to include older users in the design and development process, it is also incomplete. Many users, including older adults, are susceptible to editing their true experiences and feelings. It is hard for many to admit difficulty with what most people may find easy or to voice frustration with the loss of function. Moreover, most older users and caregivers are not familiar with what design and technology innovations are possible. Therefore, in addition to asking older users to report on their experiences and perceptions, the MIT AgeLab applies radical empathy in its research.

MIT AgeLab's Age Gain Now Empathy System, or AGNES, is equipment worn by a student, engineer, designer, marketer, developer or planner to gain a modicum of experience of what it might be like to be older and to manage selected chronic diseases, e.g., arthritis.⁶ AGNES includes equipment from head to toe that impairs the user's vision, flexibility, dexterity, gait, balance, and more. While it is impossible to replicate what an older user experiences entirely, AGNES enables a designer or engineer to walk in the shoes of an older adult to feel the friction, frustration and fatigue often associated with using products and navigating everyday spaces. AGNES and the corresponding research processes used with 'her' enable innovators to identify challenges often unarticulated by or even

⁶ Walking a mile in another's shoes: The impact of wearing an age suit, https://www.tandfonline.com/doi/abs/10.1080/02701960.2015.1079706?casa_token=fi73V-X_sZwAAAAA:CaUeaZ3-OUJxTXHW_L8JBTYMrVeZTah3ZVSRgyGa3KQcY2M3CbRoAt0qG_R5IDRXdxroyjZ1mNvRaQ

unrecognized by older users (especially as many of them develop workarounds that they no longer notice). The system has been used to generate insights and innovations for auto manufacturers, transit operators, electronics companies, retailers and consumer packaged goods companies worldwide.

A New Vision of Old Age & Technology

Senator Casey, you may recall a distinguished resident of the Lehigh Valley in your home state of Pennsylvania, Sarah Knauss. Ms. Knauss lived to the remarkable age of 119 years old. On her 115th birthday she was asked by a journalist if she enjoyed her long life. She replied that she enjoyed her life because she “has her health and can do things”.⁷ In that short reply Sarah Knauss crystalized an ideal vision of quality aging – a vision that is not just about health alone, but health *with* the ability to do things.

Technology-enabled innovation to facility quality aging must include health but must also extend to all domains of a full life, including transportation, home, work, social connectivity, and even fun. Advances in information communications technology, artificial intelligence (AI), robotics, virtual reality, and other fields are producing promising applications to address the needs, as well as wants, of older adults.

Below are selected examples that suggest a promising technology-enabled future for life tomorrow:

Health & Safety

- **AI Home Companions** – AI home care companions are becoming more common. Some are designed for social support, others assist with specific health related tasks. Many devices are blending anthropomorphic interfaces (smiling faces or gestures) while providing automated medication or nutrition management systems controlled by voice. Moreover, these systems often enable family caregivers to monitor a person’s medication and healthcare schedule without interrupting an independent lifestyle.
- **Smart Toilets** – Toilet manufacturers are producing smart toilets that are not only easier to physically access, but also monitor various health conditions, such as diabetes.
- **Wireless Monitoring** – Low-power wireless technology is likely to supplant wearables, tracking everything from physical movement to physiological signals through walls without wearing a device.⁸

⁷ *Los Angeles Times*, December 31, 1999. <https://www.latimes.com/archives/la-xpm-1999-dec-31-mn-49362-story.html>

⁸ <https://www.technologyreview.com/s/612055/dina-katabi-emerald-walls/>

Mobility

- **Robotic Wheelchairs** – Wheelchair technology has been steadily advancing. Technology enabling self-navigating wheelchairs to assist older adults and the disabled in their homes, community and even to navigate the donnybrook of airport terminals will soon be widely available.⁹
- **Autonomous Vehicles** – Driverless cars certainly offer the promise to improve the safe mobility of older adults and the disabled. While the technology is on the horizon, more work needs to be done to understand how the technologies can be learned, trusted and safely adopted by all ages.¹⁰

Caveat: Despite the promise of autonomous vehicles, the first and last 50 feet of travel to enter and exit the vehicle remain a major technical and service challenge that may blunt the benefits of autonomous vehicles for older adults and the disabled. A person too frail, physically disabled or cognitively impaired to drive or use current public transportation alternatives is not likely to use a driverless car easily, nor will many family caregivers be easily convinced to put a frail loved one in a vehicle alone.¹¹

Home

- **Home Logistics** – There is a convergence of smart devices in the home with services provided in the sharing economy to transform the home from simply a place to the home as service platform.¹² Services for older users and family caregivers may now be coordinated through smart appliances and connected devices throughout the home, i.e., the Internet of Things. A smart refrigerator may detect that it is running low on a resident's favorite ice cream (or vegetables) and proactively order groceries. Home monitoring systems may arrange for maintenance of heating, hot water, and other systems in the home before critical failure. Technology-enabled conveniences, or life by app, created primarily for Millennials, may, in fact, facilitate a new virtual assisted living for older adults and serve as a family caregiver's partner.¹³

⁹ <https://news.panasonic.com/global/topics/2019/68529.html>

¹⁰ <http://agelab.mit.edu/avt>

¹¹ <https://www.nae.edu/208348/Planning-Designing-and-Engineering-Tomorrows-UserCentered-AgeReady-Transportation-System>

¹² <http://agelab.mit.edu/c3-connected-home-logistics-consortium>

¹³ See Coughlin, MarketWatch, This New Tech Can Turn Any Home Into A Retirement Home, May 21, 2019. <https://www.marketwatch.com/story/this-new-tech-can-turn-any-home-into-a-retirement-home-2019-05-21>

Work

- e-Learning/MOOC – Online learning platforms are no longer just for those who wish to take a single class or to address a casual interest. Massive Open Online Courses (MOOCs) now provide platforms for young and old to remain competitive in the workplace. The MIT Center for Transportation & Logistics, for example, offers the MicroMasters credential in Supply Chain Management, consisting of five courses and a final exam online. The MicroMasters credential is the equivalent of a full semester's coursework at MIT, and it can be applied for credit as part of a full master's degree at dozens of institutions worldwide. Over 280,000 learners from 196 countries have taken at least one MicroMasters course, and 16 to 20% of each run is over 40 years of age.¹⁴
- Robotics & Cobotics – While some observers worry that robots may take jobs from humans, some robotics may actually enable many people to remain in the workplace longer. Cobot and exoskeletal systems (best thought of as wearable robotics) are already in use in many workplaces, and new systems are in development. Worn by the user, these systems assist with repetitive and physically demanding tasks, thereby reducing the chances of injury and extending the physical capacity to work.

Social Isolation

- Social Robotics – Robotic applications to provide social support are booming. Social companion robots, such as Paro, a robotic harp seal, serve as a pet substitute but also provide feedback that has been shown to reduce irritability in Alzheimer's patients and to relieve some of the stress associated with loneliness. Other social robots, such as Pepper, have a more humanoid form and can remind users to take their medication, assist with navigation, or even tell jokes.
- Social Media – Life online is not just for kids anymore. While the digital divide between young and old is not closed, it is greatly narrowed. According to AARP, 70 percent of adults 50 years old and older are now on social media, and 91 percent of them report that social media is an important means to stay connected with friends and family.¹⁵ Social media platforms are developing specifically for older adults. One such example is Stitch, which unlike popular online dating sites hosts an online community of people 50-plus seeking companionship.¹⁶

¹⁴ <https://scm.mit.edu/micromasters>

¹⁵ https://www.aarp.org/content/dam/aarp/research/surveys_statistics/technology/info-2018/atom-nov-2017-tech-module.doi.10.26419%252Fres.00210.001.pdf

¹⁶ <https://www.stitch.net/about-us/>

Fun

- **Online Gaming** – Online and video games are typically considered to be the sole domain of youth, but fun is ageless. Wii leagues and other online gaming communities are now popular for older adults. For example, the National Seniors League collects statistics and organizes Wii bowling matches between senior and community centers nationwide, engaging older adults to compete, form community and have fun. Another example is the Old Timers Guild. The Old Timers Guild's own description sums up the promise of online gaming for many older adults: "we are a guild of mature gamers who have bonded together to seek out two things we are all passionate about: fun and gaming."
- **Virtual Reality** – Virtual reality (VR) offers new possibilities for older adults to travel (virtually), have fun, and, in some instances, share those experiences with others. One startup, Rendever, is bringing VR experiences to older adults in assisted living and nursing care who can no longer travel. Findings from an MIT AgeLab project with Rendever and Benchmark Senior Living found that older adults playing with VR not only had fun, but reported less depression and engaged in more active conversations with other residents.¹⁷

Technological Inequality, Digital Infrastructure & Disadvantaged Populations

Technology offers extraordinary potential to improve the lives of older adults and caregivers. However, the challenges ahead may be more complex than the technology itself.

Technology Inequality Gap

New technology is expensive when first commercialized. Technologies that were once the toys of the affluent are fast becoming the necessities of everyday living, e.g., smart phones, streaming services, WiFi. The quality of living independently or caring for a loved will become increasingly reliant on technology and related services, portending the emergence of a new technology inequality gap.

Over time technology does become affordable as sales volumes increase; note the decline in the cost of flat screen televisions and computers over the past decade. Perhaps one way to accelerate the decrease of cost of technology, particularly home-based technologies, however, is to leverage the procurement power of all levels of government to integrate selected products or services into public housing, creating greater demand and thereby lowering the market cost of technologies to improve the lives of less affluent older Americans and caregivers.

¹⁷ <https://www.springerprofessional.de/en/impact-of-virtual-reality-vr-experience-on-older-adults-well-bei/15929752>

Rural Access to Digital Communications Infrastructure

While I have already mentioned the challenges that poor design can present to the adoption and use of new technologies by older adults, Chair Collins, you are particularly aware of another accessibility barrier. Here I speak of rural populations. While many in the tech sector speak of the need for speed, rural populations, such as those in your home state of Maine, often do not even have access to the cellular service and broadband necessary to deliver many of the innovations already available today, e.g., home monitoring, telemedicine, teletherapy. This accessibility gap is unacceptable. As the nation contemplates investment in infrastructure, we must arrive at a new national consensus that infrastructure is no longer just pipelines and pavement: it includes the digital infrastructure to ensure that all Americans have access to those services that support quality living and caring.

Smart Buyer

Finally, there is a third barrier to leveraging existing technologies. There is currently a market failure in the provision of information about products that can enhance the lives of older adults or reduce the burden of caregiving. While many technology websites may include these devices, consumers do not know what they are looking for. There is no smart buyer authority to instruct older Americans and families on what to consider, what characteristics to look for, where to buy devices or services, and how to apply these innovations to meet their aging and caring needs. The explosion of startups in the aging and technology field is a grand reason for optimism, but the dearth of public knowledge, trusted advice and ultimately distribution of these innovations is a major challenge to unlocking the promise of technology today.

Bridging the Nation's Aging & Technology Innovation Gap

The nation's aging is unprecedented. While we have always had older people, we have never had this many, with more education and with more experience watching rapid technological innovation throughout their lives. The Baby Boomers are now turning 73, one nearly every seven to eight seconds. In their youth they introduced the concept of a generation gap, primarily around lifestyle. In their older age, however, they are presenting a new generation gap – that of expectations. The new generation of older adults will be neither nearly as patient nor as polite as previous generations. Throughout their lifespan schools were built, technologies developed, communities redesigned, and more. It is highly unlikely that their appetite for innovations in living will ebb just because their ages have increased.

Presently there is no department, agency, bureau, or podium to articulate a comprehensive vision of aging and innovation to meet this growing expectations

gap. There are individual examples within the government of this kind of innovation. For example, Health & Human Services and the National Institutes of Health are engaged in amazing efforts to extend life and to address the medical dimension of aging. The Veterans Administration and the Department of Education Rehabilitation Engineering Research Centers are doing exceptional work in specific assistive technologies for the disabled. But by and large, existing institutions are built upon yesterday's definitions of aging and upon yesterday's available solutions.

The recently released report by the White House's National Science & Technology Council provides a comprehensive discussion of aging and technology, but within a narrow, principally health-related frame. For example, learning or education was only mentioned six times, primarily related to health education, rather than in the context of supporting an older worker or lifelong engagement. In fact, older workers and older adult employment are hardly mentioned. The word "fun" does not appear, and play is only discussed as a transportation destination rather than an activity that older people do. Given the importance of family in quality aging, it is surprising that caregiving only appears six times. Moreover, a discussion of how technology might support the critical role of women as the nation's primary caregivers and as the majority of the nation's older population is absent. In fact, the words "female", "woman", or "women" are absent.

These observations are not a criticism; this report reflects that our institutions are unprepared for an aging population that has new and different dimensions and expectations. One possible strategy to address this gap may be the formation of an interagency advisory committee on technology and aging that includes industry, NGOs and the university research community. Whatever form this might take, it should be located within the federal structure where it might have significant visibility and power to be an agenda setter, identifying and assembling all interested stakeholders in domains that include but extend well beyond defining aging solely as a health issue.

Longevity Economy Clusters: Aging As Regional Competitive Advantage

Aging by most governments is seen as a need or problem to be solved. However, the aging population is a call to innovate. Selected governments around the world are beginning to transform their aging "problem" into an opportunity to improve the lives of their citizens and as a global export.

Singapore, Hong Kong, Newcastle, Tel Aviv and other global regions have launched aging innovation, or "silver economy," initiatives to build an infrastructure to support and leverage an aging society. Governments in each of these regions have served as catalysts to bring together researchers and businesses to address their own populations' needs, while seeking to develop a new business around old age.

In the United States two regions stand out. Louisville, Kentucky formed a coalition of health companies headquartered in that region seeking to develop innovations around healthy aging. In Massachusetts, Governor Baker launched an initiative last year to develop Massachusetts as a global leader in the longevity economy. Leveraging not just the world-class health resources in the Commonwealth, but reaching across all domains including education, finance, housing and more. This public-private collaboration involves not just startups, but will engage leading universities and major Fortune 500 companies at the C-Suite levels to develop new products, services and experiences to improve the lives of older people and their families in Massachusetts, while developing a new vision and business to export to an aging world. Inc. Magazine already recognized this work naming Boston as one of the top 20 places to start a new business because of this novel approach to translate aging into economic opportunity.

Quality Aging as a New Endless Frontier

It is my firm belief that a new endless frontier is before us – where great advances in technology are now converging with extended lifespans making it possible not just to extend life, but to improve the quality of life. By igniting a national commitment and partnership between business, non-profits, and all levels of government, we can translate inventions in the laboratory into innovations in living that will improve the wellbeing of all older adults and their families. We must view our nation's, and the world's, aging not as a problem to be solved, but, instead, as a global opportunity to write a new story of life tomorrow.

Thank you for inviting me to participate in this hearing. I look forward to providing any additional information that will ensure that all Americans live longer, better.

Senate Special Committee on Aging hearing:

“Aging and Disability in the 21st Century: How Technology Can Help Maintain Health and Quality of Life”

Testimony by Cara McCarty
 Director of Curatorial, Cooper Hewitt, Smithsonian Design Museum
 May 23, 2019

This morning I want to share with you several examples of the beneficial ways design and technology are transforming the lives of people with physical, cognitive and sensory disabilities. They are from two exhibitions I organized - one in 2018 at Cooper Hewitt, Smithsonian Design Museum, the other a reduced version featured earlier this year at the World Economic Forum in Davos. The goal of the exhibitions was to illuminate the innovative designs developed during the past decade for people with various disabilities that are improving their quality of life, expanding their options and their ability to engage more fully in life.

Design plays a powerful role in shaping our lives. When applying design sensibilities to people with physical and cognitive impairments, the shortcomings of existing products and environments, as well as societal barriers and social stigmas, are magnified. Until recently, prevailing attitudes reinforced what people cannot do, rather than what they can. And, products looked clinical, perpetuating psychological barriers and how we stigmatize the user.

By addressing the needs of individuals with extreme conditions, many others can benefit. Curb cuts in sidewalks are a prime example whose mandated purpose and function have extended well beyond the original intended users. As users, caregivers, designers, doctors, physical and occupational therapists, neuroscientists, activists and others continue to make the needs of individuals known, opportunities for design will flourish.

To illustrate, I would like to share a few examples of low and high tech solutions:

Mobility:

Making canes stylish and objects of pride empowers the user with confidence and dignity. Today, there is considerable redesigning of walking sticks, balance canes. They function better, they have non-slip handles, they can illuminate at night to help prevent falls, and interchangeable handles and tips and joyous colors let the user personalize them. People now have choice, options which will continue to expand as digital technologies are integrated into canes.

Afari Mobility Aid:

Walkers, wheelchairs, scooters for older adults often lack elegance or grace, which stigmatizes the user. They are seen as medical devices. As a result,

individuals often resist using them, and they don't venture outdoors. But as demonstrated by the Afari, an all-terrain "walker" designed by two older adults with mobility challenges, but who want to remain active and independent, these mobility aids are both useful as well as stylish. In use, it appears like walking your bicycle instead of riding it.

Connecting/communicating:

Digital technologies are undeniable game-changers for many individuals with disabilities. By augmenting the potential for people to access the world, they help fill a void that is vital to maintaining a fun, fulfilling life. Many counteract isolation, but just imagine the new-found sense of independence and possibilities for people who have dementia, difficulty moving, talking, writing, moving limbs, seeing. Digital devices are ripe for numerous innovations as we learn more about the needs of individuals.

A poignant example is Tobii Dynavox's portable, eye-gazing devices that enable people to communicate and express themselves, to give access to their thoughts and ideas in ways and at speeds previously unimaginable. In addition to the device's speech-generating capabilities, eye-tracking allows one to use their eyes as pointers to move symbols, or to type and send emails, or to edit images, films.

Daily needs: Bathing, dressing, eating:

Magnetic buttons. A man with Parkinson's disease had difficulty buttoning his shirt. His wife saw a design opportunity, not an obstacle. She was inspired by the magnetic covers of iPads and transferred that innovation to invisible magnetic buttons.

One does not need to have Parkinson's or arthritis, or a prosthetic hand to prefer magnets to buttons or snaps. This is an excellent example of inclusive design: it can easily be marketed to individuals with limited manual dexterity. It was one of the most popular products at the World Economic Forum.

FlyEase shoe:

Matthew Walzer was a college-bound teenager with cerebral palsy when he sent a letter to Nike, saying he had difficulty tying laces and putting on shoes without help. He challenged Nike to design a shoe that didn't look clunky and clinical. The result – a zip around, rear entry shoe that looks like any other athletic shoe. It is available in many colors, sizes, high-top, low-top. It's another wonderful example of inclusive design that can be worn by many people, not just someone with limited manual dexterity.

Earring aid:

I was excited to read about the recent legislation deregulating hearing aids. We all experience moments of decreased hearing, a noisy restaurant, crowds of people. Hearing loss is also one of the most common conditions impacting older adults. And, we know that people avoid getting a hearing aid for an average of seven years primarily because of the negative stigma associated with them. In

earlier generations, hiding disability was a priority. But this is changing as awareness is growing and we see people embrace their disability. They are less inclined to hide, or conceal their disability.

Even hearing aids are not exempt from personal identity and styling.

These customized, low-cost over the counter hearing aids are not dissimilar to eye glasses, which traditionally used to be called "medical appliances" until fashion designers got involved and we see what can happen! Why not glam them up? People want the same thing – to feel good, even amazing.

Prosthetic leg covers:

Particularly striking examples of this shift toward outward expression are these prosthetic leg covers. Like snap-on tattoos, they are intricately patterned, beautifully designed, and available in a variety of patterns and colors. Users can "dress" their prosthesis according to their aesthetic preference. They are also affordable and make the user feel good. So often, people with prostheses are asked about what happened so they are continually reliving their trauma. With these, the conversation turns to the appealing prosthetic. The positive reaction gives confidence to the wearer. It's not about being super human, or a poster child, but unapologetically embracing disability as part of one's identity.

Accessible Olli: A prototype vehicle

How do we design transportation for everyone? In the US, 30% of individuals with disabilities have difficulties accessing transportation. Cities, streets, buildings, buses, subways and other public spaces are not universally accessible. But as we plan for the future, when much of our deteriorating infrastructure will be upgraded and brought forward, we have a critical opportunity to optimize accessibility and design our built environment to address the needs of many.

Conclusion:

In short, design matters. What's imperative, and what distinguishes many of these recent products from previous ones, is that they were designed *with* the user. By focusing on the user, and designing *with* the user not just *for* the user, we not only understand the needs better, the product better, but we humanize design. As one design professor summarized, "designing for someone with Alzheimer's is not so much about inventing new technologies or forms, but using existing ones toward different ends. In fact, students taking his class began to see human emotion, perception and language as technologies."

According to the Centers for Disease Control, one in five adults in the US has some disability. That alone should be a demographic and economic motivator! We also know that when people feel better about themselves, medical outcomes improve. The needs of the aging overlaps with disability. In the coming decades, the world's disability population will grow as medical advances allow people to live longer, healthier and fuller lives. Most of us experience disability at some point, and more than half of disabilities are invisible.

What is needed is a mindset change. We talk about the aging population, or people with disabilities as having the problem, but isn't the real problem that many of our designs on all scales create barriers? By placing those who have been traditionally excluded central to the work of design, we not only value their ways of being, but we also reconstruct notions of inclusivity and exclusivity. Designing for inclusion spurs innovation and benefits everyone. We must shift from the medical model of disability to the social. As eloquently articulated by August de los Reyes, who is quadriplegic, "disability is a mismatch between my own abilities and the world around me. Disability is a design opportunity."



61 Winthrop Street • Augusta, ME 04330
1-800-499-0229 • Fax 207-621-0509
MLTCOP@MaineOmbudsman.org

Testimony of Brenda Gallant, RN
Maine Long-Term Care Ombudsman Program Executive Director

Before the United States Senate Special Committee on Aging

Aging and Disability in the 21st Century: How Technology Can Help Maintain Health and Quality of Life

May 22, 2019

Good Morning, Chairman Collins, Ranking Member Casey and members of the Senate Special Committee on Aging.

My name is Brenda Gallant and I am the Maine State Long-Term Care Ombudsman. As you know, the Long-Term Care Ombudsman Program is authorized under the Older Americans Act (Title VII, Chapter 2, Sections 711 and 712) and administered through the Administration for Community Living. The program provides advocacy for residents in long-term care facilities, resolving problems regarding health and safety, quality of care, quality of life and protection of resident rights. The Ombudsman Program has a forty-one year history of service on behalf of long-term care consumers. The Maine Long-Term Care Ombudsman Program's state-enabling legislation extends our role to include advocacy for recipients of home care services as well as assisting patients in hospitals ready for discharge who experience barriers in accessing needed long-term services and supports.

Thank you for inviting me to provide testimony regarding the essential role of assistive technology in supporting older adults and adults with disabilities to live independently in the community. We have observed the vital importance of this technology through our work with Maine's Homeward Bound Program, the CMS funded Money Follows the Person (MFP) Demonstration Program. Maine implemented this program in 2012. Since then, with the resources this program provides, 141 nursing home residents and hospital patients have been able to transition back to the community.

In our experience, older adults and adults with disabilities want to live in their own home whenever possible. While nursing homes are required to provide information to residents about discharge and assist with discharge planning, often the barriers are too great to overcome without additional assistance. This is also true for some hospitalized patients with complex medical needs who require additional support to leave the hospital. MFP helps overcome these barriers by assessing the needs of each participant and developing an individualized care plan to provide the services and supports needed for a successful transition back to the community. A key part of the planning includes an assistive technology assessment.

Here are some examples of how assistive technology has enabled MFP participants to gain the independence necessary to return to living in the community:

- A 58 year-old woman with a diagnosis of muscular dystrophy, was admitted to a nursing home, and resided there for 17 months. She uses a motorized wheelchair and her muscular dystrophy has impacted her ability to use her arms and affected her ability to communicate. She expressed her wish to leave the nursing home, but was discouraged by both the nursing home staff and her physician, who felt that her needs could not be met in the community. However, she was determined to be in her own apartment. A critical part of her planning was access to assistive technology. An assessment recommended an eye-gaze system that enables her to use her computer with her eyes to communicate through email and have access to the internet, as well as remote access monitoring that provides motion detectors and notifies caregivers if her routine is not followed. Additionally a remote door entry button that she keeps with her allows her to enter and exit her home and enables her to allow entry to others to her home. Despite the initial skepticism regarding her ability to live independently, she has been successful in living on her own for the past six years.
- A 49 year-old woman with a diagnosis of muscular dystrophy, resided in the nursing home for five years prior to her transition to her own apartment. She uses a motorized wheelchair for mobility. MFP funded a ceiling track lift to enable transfers to be done safely when only one caregiver is present, a smart phone and iPad allow her to access the camera installed outside her door so that she can see who is there and is able to operate an automatic door opener with her hand. She also utilizes an emergency response system that has GPS tracking so that when she is away from her apartment, the system will continue to operate and she can call for help if needed.
- A 94 year-old woman transitioned from a nursing home back to her own home. She had been admitted to the hospital and nursing home after she fell and fractured her hip. She also has macular degeneration and arthritis. Her assistive technology assessment recommended the following items: a reacher to assist in picking up items without having to bend over, an assistive device for administering eye drops due to arthritis in her hands, an electric lift chair to help her stand from a seated position and sit from a standing position, a large button flip phone with pop socket grip to allow her to more easily hold her phone, an automatic door opener to allow her time to enter/exit the home safely and a large color contrast keyboard. Additionally she uses an Echo Plus and an Echo Dot through voice command to control ceiling fans, lights and the thermostat that are plugged into the Smart Plugs. The Echo Plus allows her to make calls to family and friends. This assistive technology has enabled her to remain in her own home safely. She never

imagined she would be using this type of technology; however she has embraced it and has been successful living on her own at home.

MFP, and the access it provides to assistive technology, has enabled these participants to reside independently instead of in a more costly institution. March 2018 data from the Medicaid and CHIP Payment and Access Commission (MACPAC) finds that MFP participants were less likely than a comparison group to be readmitted to an institution in the year after transition. Additionally, quality of life surveys showed improvement in satisfaction with care and living arrangements, and fewer reports of barriers to community integration. In Maine's experience, participants have reported an improved quality of life through their ability to attend college, get married, adopt pets, and in general reported improved health outcomes.

MFP also saves money. March 2018 data from MACPAC estimates that MFP resulted in a total of \$204 to \$978 million in savings from 2008 to 2013 in beneficiaries' first year after transitioning. MFP has enabled states to rebalance Medicaid dollars from institutions back to home and community-based services, complying with the 1999 Olmstead decision mandating states to provide individuals with disabilities the opportunity to live in the least restrictive, most integrated setting possible.

Despite these successes, our Ombudsman Program is concerned that the provision of assistive technology and other services accessed through MFP is at risk. While Congress passed \$132 million for the program earlier this year, MFP is only funded through the end of September 2019. Two bills, both called the EMPOWER Care Act, have been introduced to extend the MFP Program for five years - a Senate bill (S.548), sponsored by Senators Portman and Cantwell, and a House bill (H.R.1342), sponsored by Representatives Guthrie and Dingell. These bills would continue the program through 2023 and include improvements to the program such as reducing the length of time someone must be in the nursing home before becoming eligible to transition, from 90 days to 60 days.

MFP improves the lives of older adults and people with disabilities, saves states money, and leads to better outcomes. We have seen firsthand how it has transformed the lives of Maine people who have utilized its services to regain their independence. We urge members of the Committee to support the EMPOWER Care Act so MFP can continue to make a dramatic difference in the lives of citizens of Maine and around the country.

Again, thank you for inviting me here to speak today.

Robert A. Mecca

**Aging and Disability in the 21st Century: How Technology Can Help Maintain
Health and Quality of Life. Testimony before the
United States Senate Special Committee on Aging
May 22, 2019**

Chairman Collins, Ranking Member Casey, and Members of the Committee, thank you for inviting me to testify today. I am honored to be here on behalf of people with disabilities who need assistive technology to live the independent lifestyle that so many people take for granted. My name is Robert Mecca. I will be married for 29 years this year. My wife Dawn is here to support me today. I was born with Spina-Bifida and I use assistive technology every day to live independently, work and be an active part of my community. I have been working in the independent living field for almost 30 years with over 20 years as the Executive Director of LIFT, Life and Independence for Today.

I use both high-tech and low-tech assistive devices. I use a wheelchair for mobility and portable driving hand-controls that I can put into any automatic vehicle in less than 5 minutes. I am currently looking into funding for an All-Terrain Tracked Wheelchair, as I am an avid deer hunter. This outdoor wheelchair would allow me to go into the woods where I wouldn't otherwise be able to go.

One low-tech device I use is a Reacher to get things out of high places. A few years ago I had shoulder surgery and had to use a transfer board and a power wheelchair for four months. The transfer board was a little different. It had a seat on it that would slide back and forth. This took very little effort to use. I acquired the transfer board through LIFT's Reuse program and my power Wheelchair through the Saint Marys Pharmacy Home Health, a durable medical equipment provider in my home town. If I had not had access to these priceless pieces of AT, I would have been stranded in my living room looking at the same four walls for three to four months, as I only had the use of one arm. This example demonstrates that AT is not only important for people with

permanent disabilities but it is very helpful in temporary situations to keep people independent and in their own homes!

LIFT is one of 17 Centers for Independent Living in Pennsylvania. My Center is located in Saint Marys. LIFT serves arguably the six most rural counties in Pennsylvania, Cameron, Clearfield, Elk, Jefferson, McKean and Potter counties, an area of over 5,000 square miles. We serve this huge geographical area with a staff of only six. We provide services to assist individuals with disabilities to live independently in the community. Currently, LIFT has 366 open consumers. We also receive hundreds of Information and Referral (I&R's) requests every year.

LIFT is a regional center for TechOWL, Pennsylvania's Assistive Technology Act program. As a state AT Act program, TechOWL and LIFT work together to ensure people with disabilities have access to and acquisition of the assistive technology and services they need to live in their communities. Under the umbrella of Tech OWL, LIFT provides services through the Assistive Technology Lending Library (ATLL) which is a free service that enables all Pennsylvanians with disabilities, regardless of age or disability to try AT Devices to see what best suits them before they buy something. LIFT also facilitates the Telecommunications Device Distribution Program (TDDP) for our six counties. The TDDP provides telecommunication devices to qualified applicants with disabilities. These devices allow individuals to use telephones independently. LIFT also has an assistive technology reuse program. We take donations of lightly used equipment and recycle them to those with disabilities who would otherwise not have the means of obtaining them.

As Executive Director of LIFT, I serve on the board of directors for the Statewide Independent Council (SILC), which is a governor appointed position. I also serve on the board of the Pennsylvania Council on Independent Living (PCIL). Which is a membership association of centers for independent living (CIL's) in Pennsylvania. I travel quite a bit for my job and when I need overnight accommodations I always try to arrange for wheelchair access. For someone with a mobility disability who is active like myself, things like an accessible shower, shower chair, and grab bars are essential to my independence outside of my home.

In closing, I would like to thank you for the honor of allowing me to represent people with disabilities who use assistive technology to enhance their independence and become and remain productive citizens in their communities. I would be happy to answer any questions.

Statements for the Record

Written Submission to the Record

Written Testimony of Mary Lee Fay, Executive Director, National Association of State
Directors of Developmental Disabilities Services

**Aging and Disability in the 21st Century: How Technology Can Help Maintain Health
and Quality of Life**

Hearing of the Senate Special Committee on Aging

U.S. Senate

Wednesday May 22nd, 2019

9:30 AM

Senate Dirksen Office Building 562

Thank you Chairwoman Collins, Ranking Member Casey and other Members of the Senate Special Committee on Aging for holding this important hearing and accepting this written testimony submitted on behalf of the National Association of State Directors of Developmental Disabilities Services. We commend the Committee for shining a light on this topic by hosting a hearing and soliciting information from stakeholders, and we offer ourselves to the Committee as an ongoing resource as you examine this topic and consider appropriate legislative responses.

The National Association of State Directors of Developmental Disabilities Services (NASDDDS) represents the nation's state agencies in 50 states and the District of Columbia providing services to children and adults with intellectual and developmental disabilities and their families. NASDDDS promotes visionary leadership, systems innovation, and the development of national policies that support home and community-based services for individuals with disabilities and their families. The NASDDDS mission is to assist member state agencies in building effective, efficient person-centered systems of services and supports for people with developmental disabilities and their families.

The disability community has long driven advances in technology that can be used to support individuals to be more independent and lead better lives, from mobility devices to communication devices to smart homes. Our members strive to ensure that the individuals they serve have access to this technology. NASDDDS supports our members' efforts by ensuring that technology is a core component of all of our programs, from the State Employment Leadership Network, to our Community of Practice on Supporting Families Throughout the Lifespan, and the National Core

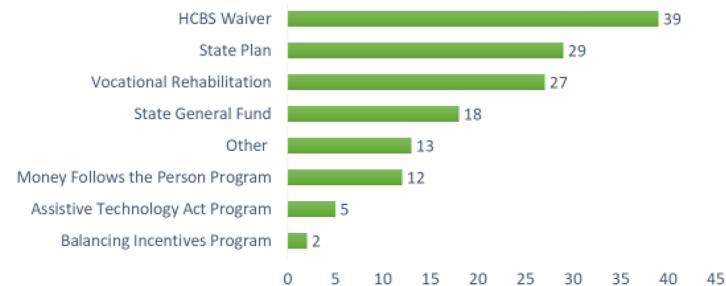
Indicators, which measures state performance. Our focus on technology has continued with the 2018 Technology Solutions State Survey, and the creation of a Technology Committee made up of representatives of state agencies focused on the appropriate implementation of technology. The NASDDDS 2019 Mid-Year Conference in June, “The Future is Now: Using Technology in I/DD Services” will focus on this very issue.

States realize they must be intentional with policies to increase the use of technology so that people with I/DD can have greater independence in managing their lives, can lessen the need for staff presence in all aspects of support, and can support the work force to be most efficient with supporting people by creating effective administrative reporting. Technology is not a panacea. Our members are wary of adopting technology solely as a means of cost cutting or as a tool for staff convenience. However, state DD agencies recognize that when appropriately deployed, technology can add value to the lives of people with disabilities by increasing independence and autonomy, while improving both the efficiency and the outcomes of services so that scarce resources can be focused on improving the service system or reaching more individuals who need services.

States are currently investing in technology solutions

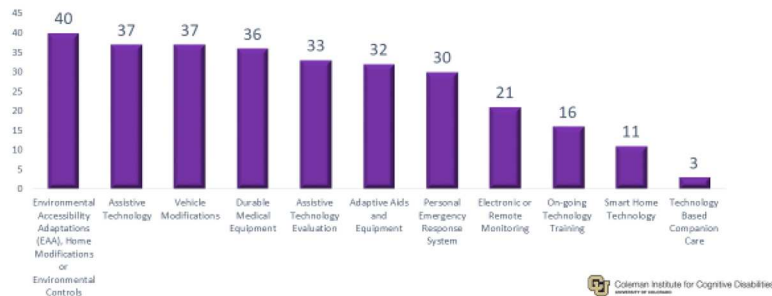
Data from the 2018 Technology Solutions State Survey, conducted by the State of the States in Intellectual and Developmental Disabilities Project of National Significance with NASDDDS as a partner, indicates that state service systems for individuals with DD are using several funding sources to purchase technology—primarily various Medicaid authorities but also Vocational Rehabilitation funds and, to a lesser extent, programs authorized by the Assistive Technology Act:

Federal Funds are Utilized to Purchase Technology Services, Applications, Devices or Other Technology Solutions



States are using these funds to purchase a wide variety of technology services and supports:

What Technology Services and Supports Does Your State Currently Fund?



However, the survey indicates that almost half of states (49%) do not fund ongoing training to learn, upkeep, and update purchased technology. This is partly attributable to the prohibitive expense of such activities in a resource-scarce system. This expense is exacerbated by several characteristics of the system, including an average turnover rate among direct support professionals across the country of 43.8%. As well, many of the technologies currently in use are app-based, and are updated too frequently to make ongoing training financially feasible without significantly detracting from the goal of state systems to provide high-quality services to as many individuals who need them as possible.

Increasing independence

People with developmental disabilities receive a variety of services through state and federally funded programs to maximize their independence and their ability to participate in their communities in a meaningful way. These services include support with activities of daily living (such as bathing, grooming, dressing, and functional mobility), instrumental activities of daily living (such as managing money, community mobility, preparing meals, and managing medications), support with community engagement and employment supports. State developmental disabilities agencies recognize that smart use of technology offers opportunities for the people we serve to increase their independence and autonomy.

Technology can allow an individual to reduce their reliance on paid face to face staff. Technology that allows an individual to learn to cook safely or to go for a walk without

supervision enhances their freedom to make choices and engage in activities independently. This in turn creates opportunities for individuals to live in more independent settings, or have fewer staff in their home, if they choose to do so.

Individuals who use remote supports, for example, might have video monitoring, two-way talk, door sensors, and other modifications that help them get the supports they need, particularly at night, without needing staff with them at all times. Kevin, an Ohioan who has used remote supports at night for several years, reports that “Remote monitoring comes in handy for me” because “I don’t need people to tell me, Kevin do this, Kevin do that. I just do it on my own time, when I feel like it.” Jeremiah, a Missourian who has Prader-Willi syndrome and experiences seizures, tried multiple settings with staff arrangements, none of which worked for him, before deciding to try remote supports. Until Jeremiah was 26 years old he was never physically alone; now he is proud to say that he doesn’t have any roommates. “I don’t have to share,” he says.

State DD agencies have also found great value in lower tech solutions that are not designed specifically for individuals with disabilities. Supports available through Amazon Echo, Apple’s HomePod, Google Home, and built-in personal software like Apple’s Siri, Samsung’s Bixby, Microsoft Cortana, Google Assistant and others can increase independence by allowing individuals to control lights, temperature, to-do lists, social contacts, and door locks. Renee, an Ohioan, appreciates her Echo because “It’s for everybody,” so when you have one, “it doesn’t look like a disabled house”—Renee is able, through use of this technology, to live in her home, in her community, just like everybody else.

Supporting the Efficiency of the Work Force

Our members are also exploring the use of technology to improve the efficiency of the workforce in the DD service system. Information technology that can connect multiple staff and make sure they have easy access to a full range of information about an individual they are serving produces efficiencies and better outcomes for people with developmental disabilities. When, for example, staff can go to one digital place to read an individual’s service plan, find out how what services have been delivered to them, check in on their progress toward their goals, read the notes of other staff, check for incident reports, and check their medication schedule, they can quickly access the information they need to provide high quality services, and identify and respond to potential issues. Solutions like this allow more time and resources to be spent on improving services or expanding access.

Recommendation

Federal support is crucial to ensuring that systems that serve individuals with developmental disabilities are able to successfully provide the benefits of technology to the individuals we serve. State systems are stretched thin ensuring that high quality services are available to as many individuals who need them as possible. Federal investment in technology for these systems would ultimately free up both state and

federal resources to improve supports, enhance quality, and address waiting lists for services.

We recommend the adoption of technology and infrastructure grants for states and service providers. Through this grant program, states could receive funding specifically for developing provider capacity to both acquire and use technology, in three categories:

1. IT support directly to providers to improve reporting infrastructure and documentation, and streamline availability of standardized data elements to provide state agencies with data needed for quality management efforts;
2. Purchasing of technology (hardware and software) that can be used either to modernize employee practices or to improve direct services; and
3. Delivery of essential training for the knowledge and skill needed for successful utilization of the technology addressed above.

Awards in the first two categories could include funding for essential training requirements, or the funding for essential training requirements could remain as a distinct funding track to make grants also available to states and providers who have already invested in technology and need support to offer ongoing training.

Conclusion

Technology already plays an important role in the provision of services to individuals with developmental disabilities, and increased access to current and future technology has the potential to transform state DD service systems. Technology must be deployed in a person-centered manner; it must be used only when it is the most effective way to address the needs of the individual receiving supports; and it must contribute to the person's quality of life. When these important guidelines are respected, increased use of technology will support a greater number of people with developmental disabilities to achieve greater independence. We appreciate the Committee bringing attention to this important topic.

NASDDDS stands ready to be of additional service to the Committee on this or any other topic involving the provision of services to individuals with developmental disabilities. Thank you again for the opportunity to provide this written testimony.

Testimony of Audrey Busch, Executive Director

Association of Assistive Technology Act Programs (ATAP)

Before the Senate Special Committee on Aging

United States Senate

May 22, 2019

Chairwoman Collins, Ranking Casey, and Members of the Committee, I appreciate the opportunity to share the Association of Assistive Technology Act Programs' (ATAP) perspective on the Assistive Technology Act, the federal investments made in Sections 4 and 6 of the Assistive Technology (AT) Act of 2004 (P.L. 108-364) and how these investments help older Americans and people with disabilities remain in their homes and communities. ATAP is a national, member-based organization, comprised of 54 State Assistive Technology Act Programs funded under the Assistive Technology Act (AT Act).

ATAP was established in 1997 to provide support to Section 4 State AT Program members to enhance the effectiveness of AT Programs on the state and local level, and promote the national network of AT Programs. ATAP facilitates the coordination of Section 4 State AT Programs nationally and provides technical assistance and support to its members. ATAP represents the needs and interests of the State AT Programs and is the national voice of the AT Programs. Our mission is to maintain and enhance a strong, effective and efficient national network of Statewide Section 4 State Assistive Technology Programs, which enable individuals with disabilities, service providers and others to learn, access and acquire assistive technology needed for education, employment and community living.

Section 4 State AT Grantees over the past 30 years have served individuals with disabilities and tirelessly pursue their core mission, which is to ensure people with disabilities have access to and acquisition of the assistive technology services they need to live, work, and attend school in their communities.

Section 4 of the AT Act provides 56 formula grants, administered by the Administration on Community Living in the US Department of Health and Human Services, to support an AT Program in each state, as well as the District of Columbia, Puerto Rico, American Samoa, Guam, the Northern Mariana Islands, and the U.S. Virgin Islands.

The 2004 reauthorization of the AT Act required a common set of activities to be provided by all AT Programs (with some limited exceptions) to create consistency among grantees. The current law requires state-level activities to include state financing and device reutilization that support acquisition of AT, and short-term device loans and device demonstrations that support access to AT. The law also requires state leadership activities that support access to AT. This includes training, technical assistance, public awareness, information and assistance, coordination and collaboration activities.

Section 4 State AT Programs are mandated to serve people with all types of disabilities, of all ages, in all environments, and to provide a wide array of activities to meet AT needs on a statewide basis.

Programs must also serve family members, service providers, educators, therapists, employers, health and rehabilitation professionals, AT vendors, procurement officials, and other interested parties.

Additionally, Section 4 State AT programs must report specific data on services provided via the required state-level and leadership activities.

The state leadership and state level activities are designed to provide a continuum of integrated AT services. The service flow begins with learning about AT through public awareness, training and information and assistance; then exploring AT through device demonstration and borrowing AT to try-

out and make informed decisions about what AT will work best. When an informed AT decision has been made, gently used AT can be acquired for little or no cost through reuse programs. Additionally, financial loan programs or other financing options are available to help with the purchase of needed equipment. Each activity within the continuum of services provides critical access or acquisition to AT.

Typically, a consumer first learns of the Section 4 State AT Programs through the state leadership activities and is then led to the state level activities. State leadership activities include training, information and assistance, technical assistance and public awareness. Training activities are instructional events, designed to increase participants' knowledge, skills and competencies regarding AT. Examples of training include large or small group classes, workshops, and presentations and can be delivered in person or via a variety of distance education mechanisms. Information and assistance (I&A) activities are those in which state AT Programs respond to requests for information or put individuals in contact with other entities. These other entities can provide individuals with information and intensive assistance on AT devices/services or AT funding. In FY 2018, a total of 221,175 individuals received I&A. Out of those, 42% were individuals with disabilities and family members, guardians, and authorized representatives, and 81% of recipients requested information about specific AT products/devices/services.

Additionally, technical assistance (TA) is provided by State AT Programs to help programs and agencies improve their services management, policies, and outcomes. As a result of TA and other activities, some State AT Programs report improved outcomes with policy, practice, or procedure that result in increased access to and acquisition of AT in the state. Finally, public awareness activities provide information on the availability, benefits, appropriateness, and costs of AT devices and services, including a statewide information and referral system. Public awareness activities can include public service announcements,

Internet outreach and social media, radio talk shows and news reports, newspaper stories and columns, newsletters, brochures, and public forums.

When a consumer learns about the State AT Program and then contacts the state program to access the services, they are led through a continuum of four integrated state-level activities, required by the Assistive Technology Act of 2004 that include: 1) device demonstration; 2) device short-term loan; 3) device reutilization (reuse and/or exchange); 4) state financing activities. Each of these four required activities provide a fluid process by which a consumer may access and interact with pieces of assistive technology and then actually decide on and acquire the correct device for their needs. Each activity is equally important as the others in the decision making and acquisition process. All activities carry equal weight and importance.

Within these four state-level activities, the Assistive Technology Demonstration Programs are the first step and provide opportunities for people to learn about and become familiar with specific types of AT by comparing and contrasting the functions and features of devices through hands on exploration. Instruction is provided by knowledgeable AT professionals in a product neutral environment that does not favor one company or manufacturer. Device demonstrations result in informed decision-making about which AT will and will not meet an individual's disability needs and prevents wasted expenditures on and abandonment of "mismatched" AT.

Extensive data that is collected each year from State AT Programs, reveal that in FY 2018, 72,559 individuals participated in 38,709 device demonstrations conducted by Section 4 State AT Programs. By projecting a modest \$100 savings realized by just half of the total demonstrations conducted has the potential to result in national savings of \$1.9 million.

And, while device demonstrations result in savings, they directly benefit the consumer. For example, a senior who benefitted from a device demonstration was an 83-year-old woman from Oklahoma. This senior was able to keep an active lifestyle, including working, when she found the right equipment to enhance her vision. Her macular degeneration caused her to lose her central vision which prohibited her from managing a computer keyboard and looking at printed reports required for her job. The Oklahoma AT Program demonstrated several items to her including magnifiers, reading prismatic glasses, and large print, high contrast keyboards to help her keep her job. The equipment and the training she obtained gave her the tools, purpose and renewed hope to continue her work at a local museum as well as many other tasks in her daily life.

Following a device demonstration, the Assistive Technology Device Loan/Borrowing programs allow individuals to borrow devices for a limited time period to use at home, school, and work. Device loans allow borrowers to try out devices in their own living, education and work environments to determine if a device will meet their needs before a purchase is made. Device loans can also provide loaner AT while a device is being repaired, while a consumer is waiting for funding approval, or to use for training or professional development purposes. Device loans result in informed and accurate AT purchasing decisions especially in unique contexts like a classroom or workplace or home setting. When a school or employer can borrow a device and make sure it will allow the individual with a disability to be successful, they save money by avoiding “incorrect” purchases.

Device loans also allow individuals to remain functional while their device is being repaired, preventing costly loss of wages, lost school days, or the need for increased community living supports. **Nationwide, in FY 2018, 32,353 device loans were made to individuals or agencies with 49,721 devices borrowed from short-term devices loan programs operated through State AT Programs. Using an average savings of \$1,000 per loan with more than one device associated results in national savings of over**

\$17 million. Projecting a minimum \$10 per day rental fee for the average loan period of 35 days, results in national savings of \$3.7 million for devices borrowed for accommodation (while a device is repaired or while waiting for funding) or for training since the device did not have to be rented for these purposes.

One of many possible examples where a consumer benefitted from a device loan is seen in the state of Missouri where a second-grade student is one of many in Missouri schools who has been able to overcome barriers to accessing print text and can actively participate in classroom activities by borrowing AT through the Missouri AT Program. The school borrowed a desktop magnifier with optical character recognition with near and distance magnification, along with instant text-to-speech functions that the student was able to try in the classroom with textbooks, teacher-produced materials, and the whiteboard to make sure it provided exactly what he needed before the school made the purchase.

Once a consumer settles on the proper AT following the device demonstration and loan activity, it is time to turn to acquiring the device. One of the acquisition state-level activities is Assistive Technology Device Reutilization Programs. The device reutilization programs support the reuse of assistive technology that is no longer needed or used by its original owner. Recipients usually obtain equipment at significantly lower cost or no cost. Reutilization efforts include refurbishment (previously owned devices are cleaned, repaired, and/or reconditioned and then provided to new owners) and the device is provided on an open-ended loan basis, until the recipient no longer needs it.

Purchasing or obtaining reutilized devices provides significant savings to agencies and individuals when compared to purchasing new devices. **In fiscal year 2018, 59,149 recipients acquired 70,673 reutilized devices yielding a total savings of \$28,075,773.** In addition, 87 percent of the reuse device recipients indicated that they would not have been able to afford the AT or obtain it from other sources if it were

not for the reuse services of the State AT Program. The cost of those individuals being unable to work, learn or live in the community without the AT they need is immeasurable.

A consumer in the state of Virginia contacted the reuse program for help with ambulation. She was using a cane funded by Medicare but now needed a three-wheeled walker that the reuse program was able to provide. A few months later, another health issue created additional disabilities, and she was unable to move off the toilet one morning. She and her family began considering nursing home placement but decided to contact the reuse program first. They provided a bedside commode to use over the toilet so that she could use her arms and be elevated for easier standing. As a result, she regained her independence and avoided premature placement into a nursing home. State AT reutilization programs yield a significant return on investment while simultaneously getting needed AT and durable medical equipment (DME) into the hands of those in great need. Many beneficiaries of reutilization are consumers who may not qualify for a cash loan, or be eligible for other state financing activities. Therefore, the opportunity to provide a reused device is critical for many consumers in need of AT/DME and should be fully financially supported.

State Financing Programs are the other state-level activity executed by State AT Programs that provide the opportunity for a consumer to acquire a device. Assistive technology state financing activities help individuals purchase or obtain assistive technology through a variety of initiatives. Financial loan programs provide consumers with affordable, flexible borrowing options. Other programs provide AT directly to consumers at no cost using dollars from non-AT Act sources or save consumers money when purchasing AT. Purchasing or obtaining devices through state financing activities saves agencies and individuals a significant amount of money and may be the only option available to them. Without the program they would go without the AT they need for work, school or community living.

There were 908 borrowers who obtained financial loans totaling \$7,867,423 to buy 933 devices. There were 3,359 recipients who acquired 4,859 devices valued at \$3,722,993 from other state financing programs that directly provide AT using external funding sources. 2,190 recipients acquired 2,333 AT devices with a savings of \$712,610 from other state financing activities, such as cooperative buying programs. The vast majority (96 percent) of recipients indicated that if the state financing activity they used was not available they would not have been able to purchase and obtain the AT due to cost or availability potentially resulting in individuals who are unable to successfully work, learn or live in the community.

A good example of where state financing activities benefitted a consumer is in the state of North Dakota, a veteran and member of the Lakota Nation lost part of her hearing due to the war and health issues. She struggled to hear and comprehend in most situations. The North Dakota AT Program was able to provide her with a personal assistive listening device through generous donations from their last resort fund. She reported that the device lets her use the TV at a “normal” loudness level preventing angry calls from her neighbors, the ability to understand her doctor during medical appointments, and the opportunity to meet with friends now that she can grasp what they are saying. She says she can even hear her cat meow. The improved quality of life she is experiencing is frankly immeasurable.

Also, in the state of Washington, a senior with severe hearing and vision loss came to the Washington AT Program no longer able to make phone calls, watch TV, and read printed material which made her feel very isolated. Through the AT program she explored several types of devices through demonstrations, and after a full evaluation, it was determined that a Google Home smart speaker would best suit her needs. The AT program was both able to provide the device through the National Deaf Blind Equipment Distribution Program (iCanConnect) funding, but also provide training on how to use the device. She now uses Google Home to make phone calls to family and friends, listen to music, the

radio, and the news, keep up with her favorite sports teams, know about any concerning weather in her location and set alarms and reminders to remain independent in her home and community.

State AT programs are an integral partner in federal, state and local AT Activities. State AT Programs leverage a variety of funding including direct federal dollars for National Deaf-Blind Equipment Distribution Program from the Federal Communications Commission along with funding from special education, vocational rehabilitation, health, senior services, and other state agencies to provide AT services. The leveraged funding secured by State AT Programs is used to expand and maximize services.

In FY 2018, State AT Programs leveraged \$21,106,708 in funding from federal, state, local and private sources. These funds were used to support all of the State AT Program authorized activities.

Although the mission all Section 4 State AT Programs are charged with is already vast, their impact often extends beyond their federal mandate. By leveraging public and private funding as well as through coordination and collaboration of activities among public and private entities responsible for policies, procedures, or funding for the provision of AT devices and services, State AT Programs are an integrated, direct services program working to form cross-agency collaborations. Examples of such coordination and collaboration are taking place across the country. For instance, Arizona's AT Program's program director met with representatives from the Arizona Developmental Disabilities Planning Council. The goal was to explore strategies for strengthening collaboration between the organizations, and to ensure that Employment First initiatives address AT issues for high school students with disabilities as part of the transition process into post-secondary education, employment, and independent living. The AT program Director now attends monthly Employment First meetings to provide input and recommendations.

Another example is the Wyoming AT Program working in collaboration with the Protection & Advocacy for Voter Access Program. Together, they hosted a training on voting and accessibility. Voters were invited to learn more about their voting rights as individuals with disabilities and were given the opportunity to use the type of voting machine that is used throughout Wyoming. The training also demonstrated the AT devices used inside the voting booth.

Additionally, in the state of Florida, due to demographic shifts in the population, the Florida AT program adjusted its service delivery model to focus more on delivering services to an aging population. The staff developed senior kits for each Regional Demonstration Center to provide device loans, demonstrations, trainings, and public awareness activities. A wide range of devices are included in the kit, such as rescue and locate devices, home automation units, medication reminders, and simple vehicle modifications.

Overall, State AT Programs play a pivotal role in annually assisting thousands of individuals with disabilities to increase, maintain, or improve their functional capability through the use of appropriate AT. In FY 2019 the AT Act received a total of \$34 million from the federal government, as part of the Labor, Health and Human Services, and Related Agencies appropriations bill. This overall level of funding provided \$28 million for the State AT Grant Programs; \$4.3 million for the Protection and Advocacy for Assistive Technology program; and \$1.0 million for technical assistance required under the AT Act's National Activities authority. **The federal investment of \$28 million that State AT Programs received allowed them to directly serve 500,000 recipients and yielded over \$63 million in savings and benefits (as that results in a return of \$2.25 for every federal dollar invested). Additionally, there was over \$21 million in leveraged funding which equate to 75 cents leveraged for every federal dollar invested.**

While it is clear that State AT Programs provide cost effective services and supports that improve the lives of people with disabilities and warrant an ongoing federal investment, four State AT Act Programs remain underfunded and do not receive the minimum grant authorized in the law in 2004 (\$410,000). These states are Wyoming, Rhode Island, North Dakota and the District of Columbia. Due to the tremendous impact these programs have on the lives of people with disabilities, and the sincere savings they yield both the government and the consumer, ATAP believes Congress must fully fund State AT Programs and raise the minimum grant authorization in the next reauthorization of the AT Act. Increased authorizing levels will directly benefit thousands more people who need assistive technology and increase the overall capacity of State AT Programs.

In preparation for a reauthorization, whether in this Congress or a future one, particular pillars must be maintained in the law that demonstrate clear success over the years. Therefore, ATAP wishes to make a set of recommendations based on information gathered through data collection across the 56 State AT Programs, and through continuous feedback and evaluation of the program since 2004. It is clear the law is working. Therefore, ATAP strongly recommends **that the next iteration of the Assistive Technology Act:**

- **Maintain the flexibility in the Act, allowing each State program to determine how to spend funds to meet the State's need; and**
- **Maintain the continuum of integrated assistive technology services outlined in the four state-level activities – device demonstration, device loan, reutilization, state financing - that maximize the ability of individuals with disabilities and older Americans across the human lifespan and across the wide array of disabilities, to increase access to and acquisition of**

assistive technology. Each of these activities is as important as the other, and all four should be prioritized equally and according to each state's unique needs.

Finally, ATAP recommends the grant authorization levels for Section 4 State AT Programs be raised to enable grantees to build greater capacity and serve thousands of more seniors and people with disabilities in need of assistive technology.

On behalf of ATAP, I sincerely thank you for the opportunity to provide testimony to the Committee and look forward to working with you as you conduct your important work.



benetech.org

480 S. California Avenue, Suite 201
Palo Alto, CA 94306-1609
t 650.644.3400 f 650.475.1066

Benetech Comments to the Senate Special Committee on Aging on “Aging and Disability in the 21st Century: How Technology Can Help Maintain Health and Quality of Life”

May 2019

Chairman Collins, Ranking Member Casey, and distinguished members of the Special Committee on Aging:

My name is Betsy Beaumon, and I am the CEO of Benetech, a non-profit organization in Silicon Valley that focuses on software for social good. We provide free and low cost solutions to support underserved populations, including people with disabilities and seniors. Our products include **Bookshare**, the largest source of accessible books serving over 650,000 people with disabilities, and **Service Net**, a social services support platform designed to increase access to services and reduce administrative costs.

Both general and assistive technologies can allow seniors and people with disabilities to continue to be valuable members of their communities, maintain connections with family, friends, and services (i.e. transportation, education, health care, leisure activities, employment, etc.) and live full and meaningful lives. Great assistive technologies abound: Screen readers open up computers to someone who is blind for education and high-level employment, hearing aids keep seniors connected to the world, and a surge in robotics can augment the capabilities of people with physical impairments, including veterans who wish to return to active lives, from employment to sports.

From the mainstream consumer perspective, new automated home products and smart speakers can allow seniors to stay in their homes longer and possibly ease the chronic shortage of caregivers for people with severe disabilities. This is particularly true when combined with specialized assistive devices and services, e.g. reading Bookshare books through a smart speaker or using specialized sensors to indicate someone has fallen and needs help. Research is underway on whether people with dementia or Alzheimer’s can benefit from additional data to guide caregivers toward issues or injuries where the individual is unable to do so. The rapid innovation in these more mainstream areas is possible due to industry-driven open standards, a broadband internet backbone that supports new players, intensive use of artificial intelligence (AI), and industry leaders who have begun to support accessibility in their platforms.

The advancement of these mainstream consumer solutions, with so much potential for social good, also have a dark side that bears government oversight, and the time is now, not in some distant future. If you have used Google, Siri, Alexa, Uber, or a myriad of other products and

services, you've already leveraged AI. AI is the brain behind all of these wonders, and what it eats is data. Every search, map, song request, purchase, or ride you take feeds the engines and informs how they work.

This data feeding frenzy poses two distinct concerns, especially for seniors, people with disabilities and other vulnerable groups. First, the data in question includes the personal data of millions of Americans, who are (often unknowingly) trading privacy for free access to services. Vulnerable populations are particularly at risk of exploitation and harm. What if the same automated home system that keeps them safe also sells (or loses) their information to bad actors, who use it to drain their accounts or defraud them? Second, and perhaps more alarming, is the unconscious bias built into much of the training data, and thus many of the AI algorithms in existence. If an automated home system is trained on typical user data from active families, will it take into account the slower movements and habits of seniors? Do smart speakers effectively "hear" people with vocal impairments? After documented studies involving bias in facial recognition and other AI systems, such questions are reasonable. Silicon Valley developers unfortunately represent a narrow slice of society, and the data they choose to "feed" the systems will determine how they operate.

Without explicit mandates for inclusive data and testing, including seniors and people with disabilities now, current and future systems will likely continue to fail this critical and growing population. And without transparency into the data and algorithms themselves, there will be no way to fix or replace them later. As these technologies drive smart cities, healthcare, and other critical civic and life-sustaining systems, it is imperative we get this right.

In conclusion, we are living in an exciting world where new things are possible every day, and, if used well, these technologies could positively impact individuals and society at large. While helping society's most vulnerable was once the purview of only specialized assistive technology, new breakthroughs mean mainstream products can also play a huge role in achieving this aim. As such products become far more entrenched in our public life, we owe it to seniors and people with disabilities to make sure their voices are heard and their interests are protected.

Respectfully submitted,



Betsy Beaumon
CEO, Benetech