**August
Newsletter**

**State of Liability
Written by Judy Wieber**

July 27th was the 34th anniversary of the Americans with Disabilities Act. It is a civil rights law, enabling people with disabilities to fully identify and own the words first set forth by the founding fathers of our country in the Declaration of Independence: “We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness.”

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Employment and the ability to earn an income make it possible to live, to have the freedom to pursue happiness, and obtain your personal goals. We here living with disabilities in Suffolk County, in the state of New York, need to be able to work, to make a living.

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When Kim Hill was appointed the Chief Disability Officer, she had planned to create 1,200 jobs for people with disabilities, working for governmental agencies.

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There are long-deferred bills in both the New York State Assembly and Senate, if passed would help qualified New Yorkers with disabilities to obtain employment working for the state, and help to keep their positions. These bills are NY State Assembly Bill 2023-A6541(sponsored by Assembly woman Kelles), and complimentary NY Senate Bill 2023-S1164A (sponsored by Senator Sanders Jr.). The bills will waive the state of New York’s government immunity to being held liable for violations of the Americans with Disabilities Act, as well as other employment protection acts.

Presently, NY State has immunity from such alleged violations. This law is asking that the immunity be removed, and that the state, like all other municipalities, private corporations, organizations, etc., be held accountable.

The bill has passed the Assembly and has made some headway in the Senate, but it needs to pass both Assembly and Senate to make it to the Governor’s desk.

Once the Senate’s summer recess is over, as members of the community of people with disabilities, let’s reach out to our state representatives and let them know how important it is to support these bills. Since municipalities are already held accountable, why should it be any different at the state level?

If writing or emailing your representative presents a challenge, SILO always invites Senators and Assemblypersons to attend our ADA celebrations. They are perfect opportunities to meet our representatives in person and mention our wants. Let’s hope 2025, the 35th, anniversary of the ADA, has one more accomplishment to applaud.



Above are some pictures from SILO's 34th Anniversary of the ADA Celebration on Friday, July 26th, 2024.



## DynavoxWritten by Gina Kranz

Watching this video, I learned a very shocking statistic. Only 2% of people who can’t communicate ever learn of a device like this. The other 98% remain silent. That’s awful! Watch this video for a deeper look inside Dynavox.

<https://youtu.be/ELpKDu4ojto>

I wanted to tell everyone about Dynavox products. These speech devices are technically referred to as augmentative and alternative communication (AAC). I received a new Dynavox last year, an SC Mini, but there are several different types of devices, addons and settings. I will cover some information, but I encourage people to visit the [website](https://us.tobiidynavox.com/) to learn about everything.

The communication bill of rights states that everyone has the right to learn to communicate, to be spoken with and not about, to know and ask what’s happening to them and to make their preferences known. Everyone has the right to a communication system all the time and deserves to have a voice. For people with conditions that impact communication, AAC is the means of achieving this basic human right.

The Dynavox website has a paragraph that I really love. It says:

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*The communication bill of rights states that everyone has the right to learn to communicate, to be spoken with and not about, to know and ask what’s happening to them and to make their preferences known. Everyone has the right to a communication system all the time and deserves to have a voice. For people with conditions that impact communication, AAC is the means of achieving this basic human right.*

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Here is the link to ASHA- American Speech-Language-Hearing association Communication Bill of Rights

<https://www.asha.org/njc/communication-bill-of-rights/>

To participate fully in communication interactions, each person has these fundamental communication rights.

ASHA lists these rights as:

* *The right to interact socially, maintain social closeness, and build relationships*
* *The right to request desired objects, actions, events, and people*
* *The right to refuse or reject undesired objects, actions, events, or choices*
* *The right to express personal preferences and feelings*
* *The right to make choices from meaningful alternatives*
* *The right to make comments and share opinions*
* *The right to ask for and give information, including information about changes in routine and environment*
* *The right to be informed about people and events in one’s life*
* *The right to access interventions and supports that improve communication*
* *The right to have communication acts acknowledged and responded to even when the desired outcome cannot be realized*
* *The right to have access to functioning AAC (augmentative and alternative communication) and other AT (assistive technology) services and devices at all times*
* *The right to access environmental contexts, interactions, and opportunities that promote participation as full communication partners with other people, including peers*
* *The right to be treated with dignity and addressed with respect and courtesy*
* *The right to be addressed directly and not be spoken for or talked about in the third person while present*
* *The right to have clear, meaningful, and culturally and linguistically appropriate communications*

To someone who can’t communicate, AAC’s are more than just a device. They’re freedom and the chance to be heard. They empower people to speak up and share their needs and feelings, and enable them to make choices for themselves.

The Dynavox software is very easy to use. Besides the great communication boards, it also offers a calendar, clock, timer, games, whiteboard and many other options if you unlock Wi-Fi. I was able to use Alexa for the first time. It has a bunch of preset commands for Alexa and plenty of room to set your own. It’s able to control smart home devices. I especially like that you can use Echo drop in and broadcast so a disabled person can easily contact everyone in the house through video or voice, and text anyone they need to.

These devices have so many different capabilities. For instance, instead of a synthetic voice, [they can use yours or someone else’s](https://us.tobiidynavox.com/blogs/product-discovery/voice-banking-demonstration-listen-to-a-natural-vs-personal-synthetic-device). They offer several different options, including an eye tracker. The eye tracker enables people with physical disabilities to control a Windows device with their eyes. This lets you replace a traditional keyboard and mouse with your eyes – surf the web, connect on social media, play games, create documents, control smart home devices and more. They also [offer their software to purchase](https://us.tobiidynavox.com/collections/apps-software) for your own device if you feel more comfortable using that.

They also have many different accessories to fit your unique needs – wheelchair and desk mounts, floor and table stands, carrying bags, shoulder straps, keyguards, handles, headmouse (like the eyetracker, but for head movements), PCEye with carrying case (a small eyetracker device that works with Windows computers and devices), the HoneyBee switch (allows certain devices to become motion activated), and more. One of my favorites is called AccessIT 3. It’s a small USB device that lets you use their TD Snap software, with your settings, on any Windows computer.

They have representatives across the United States, Canada and some other countries who help you both during and afterwards the purchase and set up process. They are extremely nice, very helpful, and are very good at securing funding too! (Note that most insurances require you to work with a speech therapist who can assess you, attest to your need for it, help set up the device and train you to use it easily)

Setting it up is an extremely important process because you can alter everything to fit your particular needs. It’s very beneficial to work with the consultant and speech therapist for this, as it’s very detailed and they are well versed in navigating the settings effortlessly. You can choose the voice, layout, speed, age range (to determine age-appropriate words and pictures), grid size (I think I have 10 x 8=80 boxes per page, while a child or someone with limited capacity might have 10 total), etc.

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They also offer so many different avenues of training or assistance. Their devices come with training cards, they have live events, support articles, a video library, zoom calls, and their consultants and phone or online support are available for you from 9am to 9pm EST.

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Do note that insurance won’t cover unlocking the internet on your device, but you can have that done for a one-time $25 fee. Just let your consultant know if you need help doing that.

Just like wheelchairs and a lot of medical equipment, most insurances will only cover a new device every 5 years so make sure you are really careful.

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This is my second product from Dynavox, and I have been so pleased with the device, the company, and the people associated with them. I would definitely recommend them!

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Here is the link to find a local representative:

<https://us.tobiidynavox.com/pages/find-a-solutions-consultant>

## Peer Integration College OutreachWritten by Michael Kohut

Students with disabilities represent over fifty percent of the population that utilize ACCES-VR services. When I began with SILO 4 months ago, I noted how countless parents and caregivers of these students relied on the program to help replace and supplement the support network their children were losing as they moved beyond primary school.

Call it blissful ignorance, but as an individual with a highly visible disability that had only limited impact on my cognition, this stage in life wasn’t fearful for me.  Instead, it was colored in my memory with excitement. An excitement for the end of IEP meetings, testing sessions, and the supervision that came with them.

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My university education was helped along by the disability support staff, and for most of my tenure as an undergraduate student that felt like enough. Ready and willing to work, I graduated, and with no lost irony, found myself in a situation not unlike those parents described above. I had grown to take the educational environment for granted, and falsely assumed I would be able to “power through” my limitations like I always had.

As I faced aging, and the changes in my ability that I should have been preparing for, there was fear, a sense of grief, and even hopelessness. Joining ACCES-VR, for me, was comparable to being tossed a life-preserver after nearly drowning. I had an incomplete perspective on my barriers, but after finding employment, a question lingered: “What if I had known about this program before I graduated university?”

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My work at SILO has helped me gain a more multifaceted perspective on the spectrum of disability. My missteps were themselves a form of luck, a privilege which countless members of the population we serve here could never hope to get. The ability to try again, fail again, and to fail better until, at last, finding success, is a luxury of class and circumstance. So how do we circumvent such factors and help others from making the mistakes that I did? Simple: we take the question that lingered for me, and turn it into an answer.

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The Peer Integration College Outreach program has been started to bridge the gap between college education and vocational rehabilitation. Our plan is to connect directly with universities across Suffolk so that ACCES and similar services are on their mind while students are learning what they want to do, and how they want to live.

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Being more aware of the barriers ahead is potentially invaluable to this population of independence-minded disabled students. And if we can help even one person avoid those pitfalls that lead to my own unhappy wake up call, that’s certainly invaluable to us!

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Contact the Peer Integration Program at SILO: 631-880-8929 x159



Pictured above: Peer Integration Program Specialists, Michael Kohut (article author) and Kathryn Snaith.

## Aphasia AwarenessWritten by Judy Wieber

June was Aphasia Awareness Month. Aphasia is the inability to speak, or sometimes it means an inability to either speak, read, write, or understand language. It is the result of injury to the language center in the brain, either through a traumatic injury, stroke, or infection.

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While working here at SILO, I have been able to meet many different people, with many different conditions. Recently, I met a woman with aphasia. Until now, we have only communicated via the computer. This week she will be coming to SILO to meet with our Adaptive Technology specialist for evaluation and training.

Though we can communicate quite easily through e-mails, it did not dawn on me how communication might be different and challenging in person until we actually met. I started to wonder how my own disability, not being able to see, might affect things?

I rely heavily on sound, and cannot pick up the body language or gestures of a person made to accent meaning. This can be frustrating for myself at times. I can only imagine how it must feel to have something to say, yet not be able to produce the words.

I want to make my new friend feel comfortable. How can I do this?

Though I have a disability, and perhaps have some empathy for the situation, it is not the same disability, and I am not an expert in the field.

So, I visited the National Aphasia Association website, where I was able to find a helpful YouTube video:

<https://www.youtube.com/watch?v=zkhlMrjsnyo>

Here I found seven tips to help communications with a person who has aphasia, using the word aphasia:

A - Ask simple questions.  Can you phrase your question as a Yes or No question? Can you ask for a thumbs up or a thumbs down?

P - Supply choices. Instead of asking an open-ended question, give a few choices to make it easier.

H - Help communicate only if asked. Do not communicate for someone, give them time and space to request aid.

 A - Acknowledge the frustration.  People with Aphasia know they have Aphasia. It is ok that they are frustrated, and to take their time to speak. We like to tell people to adjust to ‘Aphasia Standard Time’.  It is okay to relax and enjoy a slow conversation. People with Aphasia have something to say, and you do too.

S - Speak slowly and clearly. Enjoy the conversation.

I - If you do not understand, say so. It is better to let a person know than to pretend. You can ask to say it in another way, use hand gestures, or draw a picture.

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A - Allow extra time, pausing, slowdown, and connection.

## My Trip to the CapitalWritten by Judy Wieber

I had been hearing a lot about the proposed cuts to eligibility for the Consumer Directed Personal Attendant Program (CDPAP), but wasn’t too clear on what it meant for myself or others. I learned that it might mean those who use the program may need to pay out of pocket for aid with tasks of everyday living, but how could that be possible when those who are receiving the services are on Medicaid? Usually, those on Medicaid also have financial need. If you cannot afford to pay out of pocket for this help, and you are considered no longer eligible, what will happen to you? Will going to a nursing home be your only choice?

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The more I learned, the more I wanted to know. I then discovered that the program, funded by New York State, allows consumers to hire who they decide would make an excellent personal care attendant. The intention of the program puts the consumer in charge of their care, instead of an agency, selecting who will handle your personal needs. It also allows a person to live in the least restrictive environment, enabling people with disabilities the opportunity to be practical and active members of the communities in which they live. This was in accordance with the ruling set forth by the Olmstead decision of June 22, 1999.

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Informational e-mails often come to my inbox. Organizations and other consumers, asking to act by contacting our State Representatives, to stop the cuts. Then an opportunity popped up. Mr. Delgado asked if I would be interested in going to Albany on behalf of SILO, to speak about how I and others would be greatly affected.

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Word came about how Down State Adapt would be holding a press conference, and how they were inviting others to come. Joe said I could go, and I was extremely interested. It had been about 25 years since I had traveled to the capital, aside from the recent trip to rally for the MVT bill. This was a chance to publicly advocate for a worthy cause, as well as to escape my normal routine.

At first, I wondered, should I take the train? It would be two trains, boarding the Long Island Railroad in Babylon, traveling to Penn, and then transferring to Amtrak. After reaching the Rensselaer Station, I would then need to figure my transportation to the capital. However, I wasn’t too sure how I felt about traveling solo. In years past I would travel with my husband, Harold. This time I would not have my traveling partner. So, I figured I would put my feelers out to see if anyone I know was going. Gina was going, but she would be leaving at 5:15 am. She lives about 25 minutes away from me. I would have to leave at 4:51 am to be on the same train. The thought was we would meet up in Penn.

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I reflected on the days of traveling to Albany with Harold, back in the late 90’s. With both of us blind, though skilled in mobility, we still had many concerns navigating from the LIRR platform to the Amtrak station. I remember asking the conductors at the time if there might be LIRR staff who might be able to guide us. Now I know that the MTA has ambassadors, and if you give the Long Island Railroad Customer Service two hours’ notice before arriving in Penn, they will send someone to assist you.

Now, I am a middle-aged woman who is more used to doing things locally with my family. After Covid even my brothers, who would go to the city for concerts and shows, stopped going to Manhattan. But I thought my kids might like to take a trip. My daughter, a high school junior studying US government, might find it to be worthwhile? Though taking her out of school was not really something I wanted to do right now, with the social studies Regents right around the corner. Fortunately, my son Hayden, now a college sophomore, offered to save me the headache of traveling by myself.

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I would like to mention here how navigating to the Legislative Office Building is not an easy task. The capital is a huge place. I had been there 25 years ago, navigating with a guide dog. Now a cane user, all the mobility training I had received in the past would not fully prepare me for the walk I was about to embark on around the capital. As a middle aged, blind woman, who sits at a desk most of the day, I really put my artificial hips to the test. I was glad I wore comfortable shoes. You could find me holding on to the back of Valerie’s electric wheelchair, trotting and panting, or holding on to the elbow of Michael, a gentleman who lost the use of his hands because of an auto immune disease. We were all there for the same reason, to speak out and ask that the proposed cuts to home health care eligibility be repealed.

In the wee hours of Monday morning, my son and I hit the road. To Albany or bust was our slogan. After checking in at the Hilton in Albany, and catching a few hours of sleep, I arrived promptly at 10:30 am at the Legislative Office Building, thanks to Hayden, where I met up with others.

Members of Adapt went with a written response to Governor Hochul’s office about the proposed cuts. This was then followed by a press conference:

<https://www.dropbox.com/s/litsizribz7e6uy/Lobby%20Day%20In%20Albany.mp4?e=2&st=rzh0cykr&dl=0>

Once the press conference was over, a group of us then went to speak at Assemblywoman Davila’s office. Though I did not get to speak at the press conference, I did get to speak there. We went around the table informing her aide of the critical situation our community would be in if the eligibility cuts were not repealed.

I spoke of how I work for Self-Initiated Living Options, and how I live in Suffolk County, NY. How I own my own home, was married, have two children, one in college, the other in high school. I am 55 years old, as a homeowner, I pay taxes, and I make it my business to vote. Though I am not presently using home health care services, my family does help me with certain tasks of daily living, such as food shopping, household chores, and light cooking. Do they get paid for this? No. Should they be paid? Probably. I do as much as I can without vision, but being a working mother can pull you in different directions. Disability and responsibility can consume lots of one’s time and keep a person busy. If I wanted to not be involved, living in a nursing home perhaps wouldn’t bother me so much. But then I also would not have the life experiences I have had and memories I have made. I would have probably never married, had kids, bought a home, or worked, and that would just not be me. I like living and contributing to the community in which I live. I want to be living up to my greatest potential, in the least restrictive environment. I believe in people staying in their own homes for as long as one can. And perhaps one of the biggest motivators, is that my husband died in a nursing home, at the age of 48.

There is ‘talk’ of how those presently receiving home health care could be grandfathered into the program. However, that still must be put into writing. Though I am not receiving these services, I might still be a suitable candidate to receive them, if not now, soon. I would not be grandfathered in. This would break my spirit and rob me of so many life opportunities. And as I said earlier, that just would not be me.