**December
Newsletter**

**Health Care With Dignity
Written by Judy Wieber**

On October 18th, SILO held their annual Self-Advocacy Conference. One of the workshops provided was a panel discussion pertaining to healthcare, and the positive and negative experiences a person with a disability may confront. This panel discussion grew out of a committee formed at SILO to have an impact on the way the medical model interacts and provides medical care to people with disabilities. I, as a person who is blind, and who receives medical care, speak from my own perspective and the changes I see need to be made to the present medical model. I was to be a backup panelist for the discussion, but because all panelists were present, time did not allow for my presentation. The following is what I would have contributed to the discussion if time had allowed:

The following story is a culmination of experiences, regarding a typical doctor’s visit.

My SCAT is late picking me up, and so I arrive at the office late for my appointment. I go inside and am greeted by a kiosk I cannot use because it is not equipped with screen reading software. I try and grab the attention of a row of very busy receptionists who do not acknowledge me standing there, to let them know I need to log in for my appointment. I am told to take a seat once they have my name and insurance information. No one offers to find me a seat. I nearly sit on top of another patient because no one answers my question: Is there an open seat? The person I nearly sit on, then directs me to an open seat. A medical receptionist comes out from behind the desk to ask me if I would mind filling out a printed questionnaire about my medical history? I let her know, I cannot read the questionnaire because I cannot see the print. She then apologizes and I ask would someone be able to go over the questionnaire. She sits down next to me, and she asks what do you need read? Well, I cannot see any of the questions. Maybe you wouldn’t mind reading a few questions, so I know what it is you are looking for. She proceeds to ask the following question, out loud:

* What was the medical history of your mother, father, and siblings?
* Do you smoke?
* How many alcoholic drinks do you have in a week? A month?
* Are you sexually active?
* When was the date of your last period?

All of which I do not wish to answer in the middle of an overcrowded waiting area, and, therefore, do not answer. So the receptionist hands me the paperwork, and lets me know I can fill it out later and bring it back next time.

I then wait for what seems like an eternity to be called in for my visit, a result of arriving late. My name is finally called. I stand up and head towards the voice, trying not to trip or bump into anything or step on any feet.

I say hello, I am Judy Wieber. What is your name? She tells me her name is Sally, and that I will be waiting for the doctor in room number three. As I maneuver down the hallway in the incorrect direction, I am grabbed by Sally, who tries to direct me to room number three from behind, her hands on my waist and elbow. I am getting slightly pushed in the direction she wants me to go, nearly tripping over the threshold. I am now told to take a seat over there and the doctor will be in to see me soon.

I use my cane to find a chair. The chair I find is on wheels, it has no back, and no arms. I go to sit down and sitting on the edge the seat moves in the opposite direction and I land on the floor.

I am not injured, thank God. Though they cannot understand why my blood pressure is now high.

I am not asked to step on the scale because it will be too difficult.

While I wait for the doctor to come in, a few people come in and out and they do not let me know who they are. They are talking to each other, and one asks me a question which I do not realize is directed towards me, since they do not let me know that they are talking to me.

The doctor comes in, says hello, and asks me how I am feeling. I let him know my symptoms. He hands me a paper with the name of a specialist he wants me to see and paperwork for some labs he wants me to have done.

Both items I cannot read, but I have brought along my voice recorder to take notes.

I then am escorted out, but this time I ask if I may show them how to give proper sighted guide, and if they can be very specific with their directions, i.e., do I need to turn right, or go straight?

Now I have missed by SCAT and must wait for the service to send another bus.

As I wait for my ride, I receive a text message on my cell phone from CVS pharmacy that my prescription is ready for pick-up.

Now, I have notes on the specialist I am to see, and the labs I am to have done, but I do not have any notes about and do not recall being prescribed a medicine. I call my pharmacy and ask the name of the medicine and for what reason it has been prescribed. I am then informed that it was an error, and that I should disregard the text.

It was a good thing I asked questions and took my own notes, because I cannot read any of the information and have a hard time pronouncing the names of these tests and medications, let alone try to spell them back without having a visual reference.

These are the types of experiences that have occurred over the years while attending various doctor offices. Of course, if they happened every time and all at once, I am not sure I would attempt to even try to do things independently. Much of this I would say is a lack of good, clear communication, and a lack of experience with the blind or visually impaired. People, including those in the medical field, get uneasy, not wanting to ruffle anyone’s feathers, so often we forget to ask questions. We avoid what we feel might be an uncomfortable situation, pushing it under the rug. We cannot expect everyone to know everything about our disabilities, but we can, in a kind way, try and share to bring about understanding.

How about you? Do you have any stories you would like to share about your visits to the doctors, or hospital? Let us know by writing us at the newsletter.

 **Patrice: The Movie
Written by Judy Wieber**

Recently, it was suggested that we review movies about people with disabilities. Patrice: The Movie was recently mentioned as a possible movie for a movie night here. Though at present, SILO does not have a movie night, I decided to review the documentary.

I want to start out by saying how I really loved this movie. The love shared by Patrice Jetter and Garry Wickham is so genuine and authentic. It breaks your heart that they can not get married, for fear that they will lose their Medicaid benefits on which each is dependent. It depicts the struggles of independent living and wanting to have a part of the American dream. It also shows how the human spirit will not be broken under strained circumstances. “Where there is a will, there is a way.” It questions and challenges the rules of our state governments about who is eligible for Medicaid and the income parameters that restrict eligibility, and the cause to advocate for marriage equality for all!

The documentary also highlights the talents and strengths of all the cast. From Special Olympics athletes, to artists, to outstanding analytical people, and strong advocates, the couple confronts life’s difficulties as a team, instead of pulling them apart it certainly brings them together.

At the end of the documentary, it shows a website you can visit if you want to learn more about marriage equality and how you can help. It is a feel-good movie with an action plan to right the wrongs of our society.

I give it two thumbs up.

**Advocacy and Empowerment Team
Written by Judy Wieber**

Recently, some of the members of the Advocacy and Empowerment Team did some traveling. They traveled to the Mastics-Moriches-Shirley Community Library, as well as the Veterans Administration.

The trip to the library was to see a demonstration of three new technologies for use by all library patrons. Last year, the library bought an OrCam Read, a Looky handheld magnifying device, and Zoom Text Software. The OrCam Read, in what seems like seconds, reads aloud printed material. The Looky magnifies text to 5 times its regular size, includes a built-in light to illuminate the print on a page, and can reverse the color of a page to black and the color of the print to white, making contrast greater for those with Macular Degeneration or Glaucoma. Zoom Text is a software that enlarges the print on a computer screen so patrons with low vision may use a computer.

The library wants to get the word out, so if you know of anyone in the Mastic Beach, Shirley, and Moriches areas who might be helped by such devices, please send them to the Mastics-Shirley-Moriches Community Library and ask for Kerrilynn. I am sure they would be happy to give you a quick lesson.

On October 16th, a visit was made to the Veterans Administration to acknowledge White Cane Awareness Day, and to say thank you for the service that veterans who lost their sight gave to our country. The proclamation set forth by Lyndon B. Johnson, proclaiming October 15th White Cane Awareness Day, was read aloud. A barbecue was sponsored by the Elks Club. We also learned about a golfing Club for veterans called “Out of the Rough”, and another not-for-profit organization that helps homeless veterans furnish their apartments after receiving home placement.

If you are interested in asking your own library to buy some or all these technologies, or for more information about either one of these support services for our Veterans, contact Marilyn Tucci at SILO, (631) 880-7929.



 **Blindness Etiquette for Medical Staff
Written by Judy Wieber**

1. It is helpful if staff identify themselves, especially when entering a room.
2. Speak directly to a person with a visual disability.
3. Give specific directions, such as “the chair is two feet to your right” (from the perception of the patient).
4. Try and give an accurate picture!
5. Get the patients attention by touching their arm or by using their name, so the person knows you are speaking with them, and not someone else in the room.
6. If it seems a person is struggling, introduce yourself, and ask if you can be of assistance.
7. Assist when a person is requesting assistance. Ask them what the best way to assist them is.

**Tips to Being a Sighted Guide
Written by Judy Wieber**

1. Allow the person you are guiding to hold your elbow.
2. In tight spots, move your arm behind you so the person you are guiding can walk behind you and follow single file.
3. Pause briefly at curbs, flights of stairs, and other changes of altitude.
	1. Inform the person you are guiding if the altitude change you are approaching goes up or down.
	2. Allow them to locate the first step and handrail before proceeding.
4. Inform a person of doors, the direction they open, and location of the doorknob.
5. Use words like straight ahead, on your left, turn right, etc., using specific directions.

[**Click Here for
*Hospital Adventures***](https://ginaovercomes.com/hospital-adventures/) **Written by Gina Kranz**

**Tiffany’s Story
Written by Judy Wieber**

Due to an accident just after birth, Tiffany developed Cerebral Palsy. Realizing that something was wrong, her mom immediately enrolled Tiffany into an early intervention program, called Stepping Stone, based on Long Island. It was here where Tiffany was helped to reach developmental milestones.

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The program itself is a multifaceted one. Families collaborate with social workers, physical therapists, occupational therapists, special education teachers, and speech pathologists. All work as a team to help children sit, stand, crawl, talk, feed themselves, and learn how to dress. Children receive socialization, and families receive guidance. The goal: to achieve educational excellence.

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Tiffany went on to a public mainstream school in Queens, then graduated in 2002 from Long Island City High School. Without realizing it, Tiffany started her advocacy career in high school. “A teacher asked me if I would like to represent other students with disabilities as part of the Student Council. I said sure.” Representing those students, Tiffany advocated for work tables that were better designed for students using wheelchairs, and better regulation of the use of the high school elevator.

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Tiffany credits her mom for always putting her into programs where she could socialize and develop relationships with people her own age. Her siblings and family always treated her with love and understanding. Realizing her need to partake in all aspects of life, “I can remember playing hide-and-seek with my older sister, Jackie, and snowball fights with my older brother, Valentino. They would gather up the snow, form it into a ball, and let me fire away. My younger sisters, Vanessa and Kelly have always been a source of encouragement to me, whether it was staying up with me late at night while I would  write my college papers, or saying a kind word, letting me know they believed in me."

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When asked what some of her dreams and aspirations she had for herself as a young person, Tiffany responded: “At one time I thought I would like to be a teacher, a lawyer, and even an actress. Often the response to this from others was: ‘Well you know that requires a lot of work,’ or ‘How will you do that with your disability?’ When you hear resistance, you start to think, well? What can I do?” Doubt in herself started to set in. Tiffany and her family, however, did not give in to this negativity. Her family and a neighbor with a disability were always supportive, encouraging her to reach for her goals. Tiffany remained positive and confident.

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Inspired by her own experience being a medical patient as a young person, Tiffany took coursework in health care. Before landing a position at SILO in the Advocacy and Empowerment Team, she graduated from St. Joseph’s University with a bachelor’s in health care administration. After graduation, her goal was now to find employment. Again, finding resistance from prospective employers and internship supervisors, Tiffany went to Access VR for job placement services. Access VR wanted to place her in ‘on the Job training’ in a credit card company. This clearly was not the path she wanted to take, for herself. “I wanted to do something more meaningful. I wanted for my employer to hold me accountable and responsible for my work. I wanted to hold a job that makes a difference, that has meaning.” Most of all, Tiffany wanted to help others, especially those who were struggling with disability.

Unfortunately, Tiffany’s story is not an uncommon one. Often employers must be convinced that a prospective employee with a disability can produce results and carry their own weight. Here is where the challenge arises. To land positions, you need prior experience, but how do you get this experience when you are not given an opportunity to prove yourself?

What separates those who get employed from those who struggle with this life goal is determination, and having a plan that needs to be met. Knowing what you want and communicating this to others seem to be the key, plugging away at your goal even if it is a little bit at a time, so that the goal is achieved. These are all traits Tiffany, and others I know with disabilities who are successfully employed, possess. I can see why Mr. Delgado hired her to be part of SILO’s Advocacy and Empowerment Team.

One thing I discovered while talking to Tiffany is that she holds a certificate as a Peer Specialist which she obtained in 2021. Tiffany looks forward to advocating for young people transitioning into the workplace. She hopes to help make it easier for the younger generation of people with disability. Some advice she would give young people is to never give up on your dreams. You can do whatever you would like to do, even though you might have to go about it in a different way. Never be afraid to speak up for yourself, especially when you feel as though you are not being respected or understood. Using the analogy that her disability is like taking care of a child: “. . . When children are little, you may have extra work, but you put the needs of the child before your own, because you love the child. When you have a disability, you put the needs of the disability as a priority. You must think ahead, plan your route around obstacles, which at times can seem like a lot of extra work, but because you love yourself and the person you know you can be, you work with these obstacles and take them in stride, so you can continue down the path to success.”





***\*Stocking Stuffer Idea\**
SpillNot: A Hands-Free Solution with Room for Improvement
Written by Jill Cuyar**

SILO recently ordered two SpillNot devices to test out and add to our TRAID closet, available for loan. The SpillNot is an ingenious product that leverages the principles of physics to keep your drinks stable while you're on the go. By attaching a string to the trayed device and swinging it in a circular motion, the centripetal force keeps the liquid securely within the cup, preventing spills. This innovative approach offers a hands-free solution for carrying drinks, making it a convenient option for various situations.

One area where the SpillNot could benefit from improvement is the adjustability of the strap. The current loop design, while functional, might be too restrictive for some users with larger hands to put around their wrists, which eliminates that option. Introducing a more flexible strap, such as one using Velcro, would allow for a wider range of hand sizes and provide a more secure fit. This modification would make the SpillNot more accessible to a broader audience.

Beyond its convenience for the general population, the SpillNot has the potential to significantly benefit individuals with disabilities. For example, people with mobility impairments or limited hand strength could use the SpillNot to transport drinks independently, reducing their reliance on assistance. Additionally, individuals with visual impairments could rely on the tactile feedback of the string to navigate and avoid obstacles while carrying their beverages. At SILO, we tested this device with a white cane user who is blind, as well as hooked it onto the handle of a rollator and walked around the office while balancing a plastic cup filled with water on the device. This device did in fact work as intended and did not spill the beverage while on the handle of the rollator. It swayed a bit much around the user’s wrist, but was more balanced when the strap was held with one or two fingers. It is very important not to untie, remove, or tamper with the strap of the SpillNot, as it could throw off the balance of the device or security of the strap.

In conclusion, the SpillNot is a clever and practical product that offers a unique solution to the common problem of navigating with a beverage without spilling it. While the current design is effective, incorporating a more adjustable strap would enhance its usability and accessibility for a wider range of individuals, including those with disabilities. By considering the needs of diverse users, the SpillNot can become an even more valuable tool for promoting independence and convenience in everyday life. With the holidays approaching, the SpillNot could make a great stocking stuffer for anyone who loves their beverages and wants to keep them spill-free.  You can purchase the SpillNot on Amazon.com.

We give it 4 stars!





SILO's TRAID/ATAEP Director, Oscar Salgado testing the SpillNot device on the handle of a rollator with a plastic cup filled with water.