**October
Newsletter**

**2024**

 **“Blind Barbie” – How Do we Feel About Her?**
Written by Judy Wieber

Did you hear? Just in time for Christmas, Mattel, in collaboration with the American Council of the Blind and the American Foundation for the Blind, have released “Blind Barbie” or, better yet, “Barbie who is Blind.” To show how Mattel wishes to include all in the Barbie World experience, a very fashionable Barbie is now equipped with a mobility cane, used by people who are visually impaired, and a pair of sunglasses to protect her eyes from the sunlight. Mattel, consulting organizations for the blind, created Barbie with an offset eye gaze; her eyes are looking up and to the right, showing that she is unable to focus on a visual image. Her packaging also has some braille, and I am told her clothing has different tactile textures.

Barbie’s iconic status will no doubt help children of all ages to accept and invite all to play and be included. Finally, after 65 years of this doll’s existence, I now know “What She is Made For”.

Though this is the very first Barbie with no or low vision, Mattel has also created Barbies with wheelchairs, and Barbies representing people with Down Syndrome as part of their collection.

In 1997, Mattel created a Barbie who used a wheelchair, but she could not use the elevator in Barbie’s Dream House. A girl with Cerebral Palsy made Mattel aware of the inaccessibility. Instead of making the Dream House accessible, Mattel opted to create a Barbie Olympiad with a leaner chair that would access the elevator more easily. And let’s face it, that fit in line with Barbie’s ‘cream of the crop’ image. Mattel changed Barbie instead of changing the environment. Isn’t that what we do as women? Do we primp ourselves, apply makeup, wear the best of clothes and jewelry, date the perfect looking guy? All of this is promoted in the world of Barbie, if you look perfect then you are ok, you are accepted. Then again, Barbie does live in a Dream World. And if I lived in a Dream World, a fantasy world, I would not experience troubles, disease, disability, discrimination, or hate. Unfortunately, I believe this is called heaven.

I am not trying to sound too preachy here, but we all have the ability to try and make our world ‘heaven-like’ for each other by, rather than making ourselves look perfect, changing our environment (which does include all people), realizing everyone has something to offer and a talent to be shared for the benefit of all, in order to make our world a little happier. Could we maybe choose toys for our children, the tools we use to teach our kids about life in a fun way, which help to build character and make life easier for all? Isn’t that “what we are all made for?”

I recently read a post online about Barbie who is blind. The post talked about how the writer was going to use Blind Barbie as a teaching tool, taking an opportunity to teach kids about why a person uses a white and red mobility cane, and how people who are blind read braille since their eyes cannot see the print on a page. This also opens up conversation about other assistive devices for people with low vision and no vision use, such as screen reading software, voice synthesizers, and VoiceOver on the Apple iPhone. Hey Mattel, and other toy makers, what do you say?

So, I would like to challenge Mattel once again, and ask for some accessories for Barbie’s Dream World that are already included in Judy’s Dream World: an accessible elevator, an accessible van, sidewalks with curb cuts and location dots, blue painted parking spots, accessible traffic lights, a back pack equipped with a tiny computer and pretend cell phone with a synthesized voice.

**Meet Lori Connelly
Interview by Judy Wieber**



This past weekend, I got to interview Silo’s newest Secretary of the Board, Lori Connelly. Lori had been serving on the Board of Directors for the last two years as a member and is happy to now serve as an officer.

The motivating force behind her volunteerism is her desire to give back. Her hope is that the work she does for the board will help SILO’s mission, which is to empower and educate SILO’s participants and families to gain more control over their lives through self-advocacy and self-directed programming.

After being married to her husband for 47 years, Lori lost her husband to the early onset of Parkinson’s disease. According to the World Health Organization, Parkinson’s disease is a degenerative neurological disorder that can affect walking, talking and cognitive functioning. Though Lori was an Administrative Assistant to the principal of a BOCES school for students with special needs, when the diagnosis came in, her family was in need of help.

Lori explained how grateful she was for the support of Joe Delgado and the staff at SILO. “SILO was able to help in getting a walker, wheelchair and other supplies as the disease progressed.”

She also mentioned that, while technology and understanding have advanced, there is still much to be done. She recalled a time when taking her husband to the doctor and, though they were parked in a parking spot for the disabled, the door for people using a ramp was located around the back of the building, and that it was not an automated door. It made it difficult for a person assisting a person using a wheelchair. The inaccessibility of the door made it virtually impossible for a person in a wheelchair to maneuver. This is why SILO is so important, she says, educating others on how to self-advocate for access.

We also reflected on her years as an Administrative Assistant:

Q: High school students, regardless of disability, can be challenging. At this age young people can be strong spirited and run the gamut of emotions. What was it like?

A: “I always tried to stay upbeat and cheery. Some students liked me, and if sitting in my chair would help to calm a student down, they could sit in my chair at my desk until they calmed down. I treated them like they were my own kids. It was important to have structure, and discipline.”

Q: I hear that you run a highly organized office, what advice would you give?

A: “Strong organizational skills are especially important. I am very OCD when it comes to organizing. I like to make things easy, like an assembly line. For example, if we had to send out a mass letter to parents, I would break the job down. First fold the letters, put them all in the envelopes, and then seal them. It makes things easier and quicker.”

Always being courteous, calm, and collected when things get stressful. Strong typing and bookkeeping skills. These skills are not only needed in this kind of work, but by today’s youth, regardless of what career path they choose.

Lori credits her own mom, an Executive Secretary, for guiding her to take secretarial classes.

“My dream was to be a stewardess when I was young. And my mother would say, ‘Well just in case you are not a stewardess, why not take some typing, and some business classes?’ And that is what I did. I took typing classes, bookkeeping, business math...”

For fun, Lori can be found organizing fundraisers for her Church, going to festivals with her friends, playing computer games to keep her mind sharp, and enjoying time with her grandchildren who, along with her daughter, now live with her. I found her to be a pleasure to speak with, a very humble and thankful person, willing to lend a helping hand. By the end of the interview, I was not sure who was interviewing who? She is an incredibly good listener who seemed genuinely interested and supportive, and a brilliant choice for Board Secretary.



**Adaptive Fashion for Women**

Check out this company offering adaptive fashion for women-

<https://ladyfines.com/>

**Hedwig's Retirement**



On September 6, 2024, we honored and celebrated guide dog, Hedwig, on her last day of service here at SILO after almost 6 years. Hedwig is the 5th guide dog of our Advocacy Director, Marilyn Tucci, and has been a loyal and trusted worker, hero and friend. She will be missed!

**PIP Rally
Written by Kelsey Kalafut**

SILO’s Peer Integration Program (PIP) recently hosted a highly successful PIP Rally Breakfast, bringing together staff from SILO and ACCES VR to foster collaboration and strengthen partnerships. The event showcased the comprehensive services SILO’s Education and Transition departments provide to empower individuals with disabilities and celebrate the impactful work being done across our organization.

The morning began with a welcome from SILO’s CEO, Joe Delgado, who reflected on the organization’s recent achievements, including the opening of Pathway to Wellness, our new mental health clinic. Joe’s remarks highlighted SILO’s commitment to providing mental health support, ensuring our community has access to essential mental health services while celebrating the organization’s continued growth and success.

Following Joe’s introduction, Brian McIlvain presented the OPWDD process, providing insights into his work supporting individuals with developmental disabilities. Brian shared how he helps participants navigate the OPWDD system, ensuring they can access the critical services and support they need.

Next, Kelsey Kalafut, LMSW, highlighted the recent successes and growth of the Peer Integration Program (PIP). This event rides the coattails of the exciting news that PIP has not only seen growth in 2024 but also secured a renewed contract, ensuring SILO can continue offering vital support for years to come. Kelsey emphasized the program’s impact, helping more individuals with disabilities gain independence and maintain employment.

The morning’s presentations also included inspiring real-life stories from Kathryn Snaith, LMSW, and Michael Kohut, two of SILO’s dedicated Peer Specialists. Kathryn and Michael discussed how their work with participants has transformed lives, leading to better outcomes in both independence and employment. Their stories were a powerful reminder of the tangible, positive changes SILO’s programs bring to those we serve.

SILO’s remaining Education and Transition departments then took the floor to share their expertise, showcasing the broad range of services we provide:

• Ecaterina Henter presented on Benefits Advisement, highlighting how SILO assists participants in understanding and accessing the benefits they are entitled to.

• Ryan Criscione introduced TRAID, focusing on the importance of assistive technology in improving the quality of life for individuals with disabilities.

• Oscar Salgado shared his work with ATAEP, which provides adaptive training to help participants succeed in the community.

• Gregory Runfola discussed SWTCIE (Subminimum Wage to Competitive Integrated Employment), detailing SILO’s efforts to help participants transition to competitive employment opportunities.

The PIP Rally Breakfast was a resounding success, reinforcing the power of collaboration between SILO and ACCES VR. By sharing knowledge and resources, we’re continuing to strengthen our collective impact and empower individuals with disabilities to achieve their personal and professional goals.

As we move forward, we are excited to continue building on these partnerships, expanding the reach of our programs, and making a positive difference in the lives of those we serve.

 

**Banana Bread
Recipe by SILO Advocacy Director, Marilyn Tucci**

Three ripe bananas, mashed

1 cup of sugar

1 egg

¼ cup of melted butter (half stick) or olive oil

1 & 1/2 cups of flour

1 tablespoon of baking soda

And a pinch of salt

Optional: Add walnuts, raisins, or chocolate chips

Combine all ingredients in a mixing bowl, then pour into a loaf pan

Cook for 1 hour and 15 minutes at 350 degrees

Check after one hour- if you can put a butter knife in it and it comes out clean, it's ready. Otherwise leave it in for the extra 15 minutes.

**Accessible Voting
Written by Judy Wieber**

With this year being an election year, SILO held a demonstration of the new Dominion Ballot Marking Device (BMD), an accessible voting machine. This demonstration was conducted by Suffolk County’s Board of Elections on September 17th in SILO’S Community room.

The BMD, available at every polling place, provides the ability to vote, privately and independently, to those with a disability. If you haven't had the chance to try one, I would like to tell you more about these machines and my past experience with them.

First, it feels like the best kept secret. If you do not know what you are asking for, it may never be offered to you. And if by chance you DO know what you are asking for, you may not find the machine set up and ready to be used. When that happens, I would encourage you to patiently wait while it is set up. I know, it’s easier to just say, “That’s ok. I’ll just have a relative help me vote because it is quick and easy.” But if time allows, make the poll worker do their job (asking politely of course), and patiently wait for them to set up the machine. Then, once you have voted, let the Board of Elections know about your experience.

This electronic piece of equipment allows a person who is print-impaired, blind, or low vision to hear the ballot read aloud. You may listen to your choices by plugging in a headset which the polling place should provide. The device is equipped with an Audio Tactile Interface, (ATI). The ATI has large, sharp contrast buttons in different shapes to input your information. If you have a physical disability affecting the use of your hands, the machine has a rocker switch interface. The accessible interfaces are adapted keypads, allowing you to mark your ballot.

The Board of Elections showed us how to insert the blank ballot into the machine, remarkably similar to the way you would insert a dollar bill into a vending machine. The machine then reads the contest, complete with the running candidates, and then you select which candidate you wish to vote for. You are then given an opportunity to make corrections, as you go through the different contests, or to wait until the end of your session to go back and review your choices before either printing your ballot and then casting it, or directly casting it without printing.

Unfortunately, many voters with a disability are not aware of these machines. Many poll workers are not given enough opportunity to help voters, and as a result they do not get to practice and use the training they have been given. Due to this, a voter with a disability will often opt to vote with aid from a helper instead of trying the independent option.

As an American who wishes to vote privately and independently, I find this whole experience very frustrating. It not only has exhausted my energy, but wasted the money used by the county to buy these machines.

Since many throughout the state have spoken up, much has been done to quicken the actual voting process with the newer machine. The poll worker should also be asking you things like: how do you want to check your ballot once it is marked, would you like to print it after the ballot is marked and then cast it, or would you like to have it automatically cast without printing?

If voters do not use them, and let the county know of our experiences using them, they will sit in a box, collect dust, and break down.

Just as many who have come before us used their voices to speak up and have their words count, I encourage voters with disabilities to persist in asserting that their right to vote privately and independently be upheld in their voting places.

We wish for these machines to be available, working and equipped with poll workers who know how to set them up (and, preferably, that they be set up before we arrive).

What can we do?

When going to vote, ask to use the Accessible Ballot Marking Device. Before going to vote, call your Board of Elections and let them know you wish to use the machine and would like to find it up and ready to use when you arrive there.

Attend SILO’S Self Advocacy Conference being held on October 18, 2024, at a new venue – The Bellport Country Club. The Advocacy and Empowerment Team is providing a workshop in conjunction with Disability Rights of New York who can answer questions about voting and how to report your experiences, helping to uphold the Help America Vote Act of 2002 (HAVA).

As election time approaches, let us reflect, stop, and remember those who gave their lives in service to defend and protect our freedom.

It is a time to think about our freedom and what it means to each one of us living as American citizens with disabilities.



Judy Wieber of SILO, testing the accessible Ballot Marking Device (BMD) with representatives from the Board of Elections.