

# Disability Issues

Providing people with disabilities, their families, friends, and advocates with relevant information that enables individuals to improve the quality of their life, health and employability options.

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## REquipment Expands Free Refurbished Medical Equipment Program

by Randi Sargent

REquipment, a nonprofit program managed by The Boston Home with funding from the Massachusetts Rehabilitation Commission (MRC), announced the recent statewide expansion of the popular durable medical equipment (DME) reuse program. State funding allowed REquipment to add two additional partner programs, Stavros Center for Independent Living (Stavros) in Amherst, MA, and UCP of Berkshire County (UCP) in Pittsfield, MA, to the REquipment network. This expands the distribution of refurbished adaptive devices to residents from Boston to Pittsfield.

“Since our launch over two years ago, REquipment has given more than 700 devices a second life with adults and children who have disabilities and seniors. It was always our goal to provide the same advantage to disabled people in need throughout the State,” said Randi Sargent, Program Director of REquipment. “Thanks to support from our state legislators, we are now able to provide free, clean and safe medical devices to people in need from Greater Boston to Western MA who do not have the resources to purchase equipment or

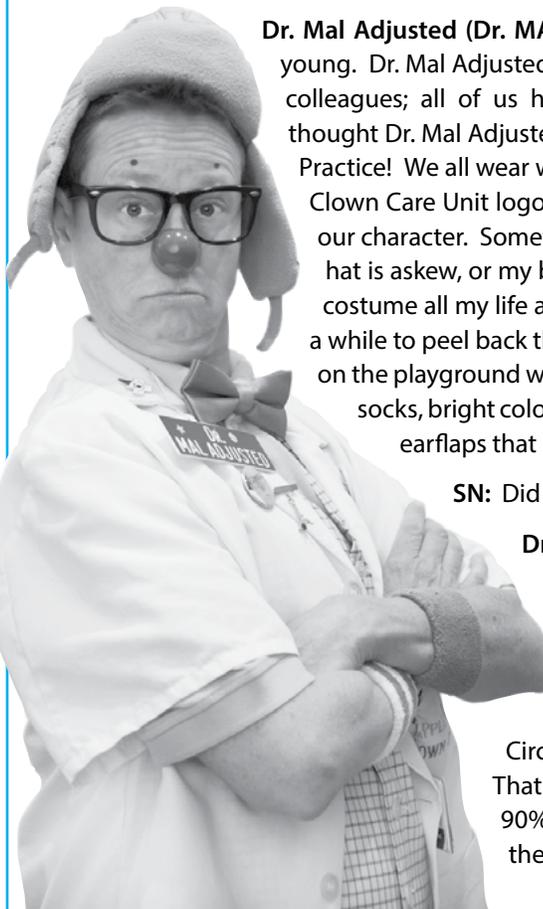
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## Clowning Around with a Hospital Clown

by Sandy Alissa Novack

Mal Malme is known as Dr. Mal Adjusted, one of the hospital clowns with the non-profit Big Apple Circus Clown Care Program. Dr. Mal Adjusted is part of a ten member Clown Care team at Boston Children’s Hospital in Massachusetts and at Hasbro Children’s Hospital, the pediatric division of Rhode Island Hospital in Providence.

**Sandy Novack (SN):** Please describe to readers a little background, your clown look, your clown demeanor and your clown name. We want to be able to picture you in your full glory!



**Dr. Mal Adjusted (Dr. MA):** I have been called Mal since I was young. Dr. Mal Adjusted was a name given to me by my clown colleagues; all of us have a nurse or doctor name. We all thought Dr. Mal Adjusted was better than being called Dr. Mal Practice! We all wear white medical coats, with the Big Apple Circus Clown Care Unit logo on the back, which we can tailor to fit our character. Sometimes I button my coat unevenly, or my hat is askew, or my bow tie is crooked. I was a clown out of costume all my life and now I’m a clown in costume. It took a while to peel back the layers of my character. I am like a kid on the playground with a Little Rascal swagger, mismatched socks, bright colored shorts, and a bright aviator hat with earflaps that my clown partners like to mess with.

**SN:** Did you always want to be a clown?

**Dr. MA:** I fell into this occupation by accident. I was always a stand-up comedian, did improvisation, and was in the theater. Then, one day a friend saw an ad listed in the *Boston Globe* for the Big Apple Circus Clown Care Unit and I auditioned. That was 19 years ago. The audition was 90% improvisation and involved lots of theater games, which I loved. I am not a

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## Clowning Around - Continued from page 1

classically trained clown like some of the others who auditioned, but, having a background in improvisation and theater really contributed to my preparation for this work.

I was invited back for the second part of the audition, which took place in a hospital. The Clown Care Program started in New York, founded in 1986 by Big Apple co-founder Michael Christensen. In 1995, Boston Children's Hospital in Massachusetts was the first hospital outside of New York that Big Apple Circus Clown Care expanded into. At the time I auditioned, the Clown Care program at Children's was increasing from three days a week to five days, so there was a need for more performers.

Being a hospital clown is all about being present, listening, being sensitive, and connecting to patients and their families. I was not sure I could do it emotionally, but I left the hospital audition thinking the work was really something special. I saw the incredible beauty of the work. A few days later I got the job offer. After several months of training, both in New York and at Boston Children's, I learned how to apply my skills as a professional performer with those needed to perform in the "theater" of a hospital, I began to discover the incredible grace, wonder, and emotional complexity of this work.

**SN:** It sounds like you were meant for this work.

**Dr. MA:** I consider myself a professional hospital clown. It is part of the fabric of who I am. The position has allowed me to understand myself better, explore what it means to be truly human, and learn about the enormous capacity of the human spirit. You walk into a room where someone may be in one of the hardest moments of their life and, sometimes, you get to see them laugh and feel joy, despite what they are going through.

**SN:** Describe your role in the hospital and how you visit people.

**Dr. MA:** The Big Apple Clown Care Program is the first professional pediatric hospital clowning program in the world, and now there are sister hospital clowning programs around the world—in France, Brazil, Germany, and Australia to name a few. There is even a two-year degree in hospital clowning offered in Israel.

One of the core strengths of the Clown Care program is that we always work in pairs. Each day, a pair of us goes on Clown rounds, working side by side. The energy we create, along with connecting to those we encounter in our travels, truly helps change the energy of the environment. As a performer, working with a partner helps create limitless magic and possibilities.

At Boston Children's Hospital, we have a set schedule each day. By the end of the week, we have been on every floor and visited almost every clinic. We are part of the Child Life Department and work closely with the Child Life Specialists who meet with us to give us the rundown as to which patients would benefit from a visit. It's very helpful and I think there should be Adult Life Specialists in all hospitals.

As hospital clowns, our job is to empower a patient. For example, the patient decides if we can come in their room. Our job is to quickly assess what is going on in the moment and respond accordingly. We allow patients to have a choice with us that they might not have medically.

**SN:** Can you give examples of a typical clown-patient encounter and a visit that challenged every inch of your clown being?

**Dr. MA:** We collaborate closely with medical staff. For instance, recently a two year old was in the hospital, and her physical therapist needed the child to get up on her feet more. The child did not want to due to pain. My clown partner played the ukulele while I knelt down and rolled a beach ball toward the patient. She smiled and walked toward the beach ball. In three to four minutes, the patient did physical therapy and the parent got to see their child laughing and joyous.

But the other day was a tough day. We were on the oncology floor a lot. A child was being discharged to hospice care. The family was distraught and understandably very upset. We talked with the Child Life Specialist and said we would go in if the patient wanted us to. The child was ten years old and we had visited with her and the family many times in the past few months. Our role was just to be present to what was going on in the room. The child was ordering everything on the menu, including whipped cream on everything. We joined in and came up with all sorts of wild things to order, a large pizza with

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**The Clown Team:** From left to right: Dr. Gon Golphin (Brian Dwyer), Dr. Windy (Wendy Kinal), Doc Skeeter (Jay Stewart), Dr. Dazzle (Meryl Galaid), Dr. Bucket Buster (Leah Abel), Dr. Gonzo (Robb Preskins), Dr. Jokulele (Joe Howard), Nurse BB (Bob Widdop), Dr. Mal Adjusted (Mal Malme). Photo: Dr. George Taylor, Boston Children's Hospital.

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## From the Editor

Dear Readers,

I just returned from attending a 5-day National Conference which was not disability focused, however it was, impressively, attuned to accessibility for PWD. During the week, I reunited with someone I had met at the conference in 2011. As is often the case, we initially connected because we both have a disability. I noticed him because he was walking while pushing his wheelchair – not your typical way of using a wheelchair!

I learned he has Spinal Muscular Atrophy, a progressive condition, resulting in a weakening of muscles. When we met in 2011, he was able to walk for short distances using his wheelchair for support, while also having it available to transfer into when he got tired. Fast forward to the 2016 conference where we were reacquainted. My friend is no longer walking behind his wheelchair. He is now using his wheelchair almost exclusively, and because of progressive weakening of his muscles, he is only able to push his wheelchair for short distances.

Each of us with disabilities creates our own adaptive ways of moving and navigating in the world we live in. With my friends' condition, it would have been perfectly reasonable for him to have upgraded to a power chair or even utilize the services of a PCA. Instead, during the conference, I watched him use the power of creating relationships and asking for help as his chosen adaptive strategy. With no hesitancy and a big smile, he asked strangers who were walking by if they could push him, explaining that he has weak arm and leg muscles. The strangers who pushed him quickly found themselves engaged in a lively conversation. With genuine curiosity, my friend asked multiple people, "What's your passion?" because he believes everyone has something they are passionate about and he loves learning about this new person. As the conference progressed, my friend had an ever expanding circle of people who waved and came over to talk with him. I realized, through his physical limitation and need for assistance, he was creating opportunities to expand his social circle by making connections with people. His disability was not a barrier, but a doorway to social inclusion.

Maybe I'm impressed because my essential way of moving and navigating in the world is, "If I can do it, I want to do it myself." I don't even have handles on the back of my wheelchair because I don't want people coming up behind me and pushing me. It's a joke with my friends that I rarely ask for help and when I do, they laughingly say, "Oh, she's asking for help!" While I believe I will continue "doing it myself" in many situations, my eyes and heart have been opened to the joy of expanding and deepening connection with others by asking for help or saying "yes" to offers for assistance. Part of my hesitancy is that my disability often becomes the focus of our conversation. But does it have to be? Perhaps I can initiate a non-disability related question, such as "What's your passion?" to introduce a topic of conversation that is more enlivening for both of us. This summer, I plan to play with this new way of moving and navigating in the world and see what happens.

Marianne DiBlasi, Editor

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## The Things Gone Unsaid and Undone

by Ms. Love

I was not feeling well and because it was during Memorial Day weekend, my primary care doctor's office directed me to the hospital's Urgent Care Center, which is one step below an Emergency Room.

I like people watching and the waiting room gave me a lot to be engrossed with. I had an opportunity to be the recipient of the kindness of a passerby when the automatic door opener to the Center would not work and I was struggling to open the heavy door. A stranger came up behind me and said she would get the door, and then smiled at me while opening it and letting me pass. I also got to smile watching the antics of a toddler with her mother inside the waiting room.

It ended up being an extended wait to be seen by the doctor, but the time passed very quickly due to a lively conversation I had with a woman who was about my age and uses a scooter which was parked a couple of feet in front of where I sat. Though in a lot of pain, I was concerned about the other woman's facial color on this hot, humid day. With some effort I got me to my feet and walked over to check on her.

"You look like you are hot. Can I get you a glass of water?" She responded, "I have a fever." Afraid of getting sicker than I already was, I took a step back and went back to my chair. The woman explained, "It's not the communicable kind of fever." She told me she had been giving her pet a bath and its sharp nail cut her. She was there because she was concerned about infection.

I nodded, indicating I had heard her. A little while later she took out a colorful embroidery project from her gigantic, colorful embroidered tote bag. I asked her if she had embroidered the tote bag. Not only did she respond, "Yes", but she also held the tote up and turned it around so I could see how she had incorporated every color of the rainbow. We both introduced ourselves and were off and running into a great conversation. I'll call my companion Lydia, a pseudonym to protect her identity. Lydia told me more about her considerable embroidery skills as well as about her past career. As she told me about her grandchild, her face lit up and gave her a respite from her current health predicament. Soon Lydia was called in for her

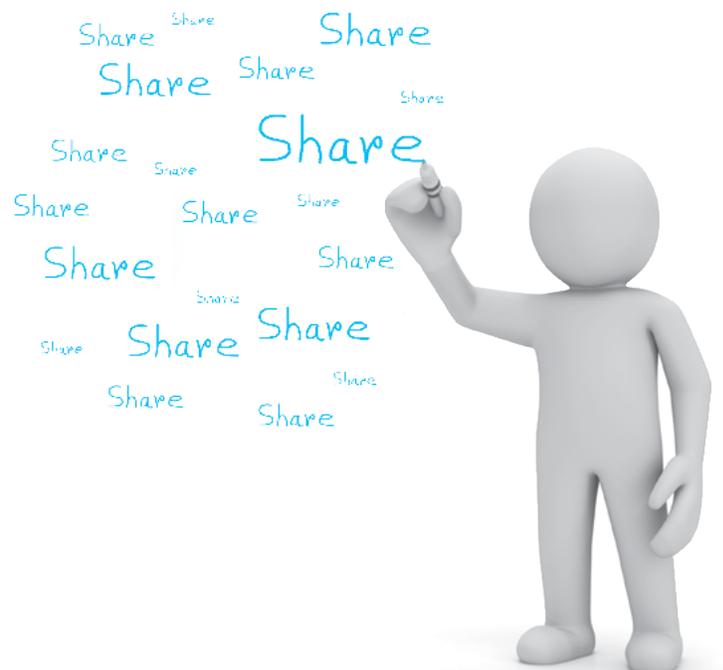
appointment, leaving me to wait for at least another half hour until I was called.

No sooner was I in an exam room than there was a commotion of activity in the hallway outside my room and EMTs with a stretcher showed up. A doctor stepped into my room and quickly closed the door behind him. I was concerned for Lydia and asked the doctor if she was okay. The doctor seemed surprised that I knew another patient's name. I explained to him that Lydia and I met in the waiting room and we had talked for over an hour. The doctor told me the matter was confidential and she could not discuss another patient's health with me. I assured her I understood, but in my head I was hearing Lydia tell me a lot about her health history and why she was especially concerned today.

The doctor took time to examine me, but when a plan for my care was put in place and the doctor was walking me out towards the waiting room, it wasn't me I brought up, but Lydia. "If Lydia comes back here, can you tell her that the woman she was talking to in the waiting room is thinking of her and wishing her well?"

If I had felt stronger, I would have headed immediately over to the Emergency Room where I had a funny feeling Lydia had been brought to on the stretcher. I thought about all the things unsaid and undone when Lydia and I had been in the waiting room, such as when she had tried to get me to share more about my health and what brought me in that day. She had been an open book, sharing about her life, her family, her health, her embroidery, why she uses a scooter, and more, while I had been reticent to share, thinking that in this day and age one has to be very careful of people you don't really know.

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**Love and Intimacy Corner** - Continued from page 4

How wrong I probably was. Lydia had only wanted to find a companion during a difficult time, someone to lighten a journey's road. If I had shared more of myself, could I have offered her a distraction from her own issues? Maybe it could have changed the conversation and frame of mind of both of us. Maybe I could have even been a breath of fresh air for her. Who knows? How many times do we wish we had said something or done something more?

All the way home, and all during the rest of the holiday weekend, I prayed Lydia was getting all the care she needed and was embroidering her way through her newest embroidery project. Perhaps she was thinking of the lady she met in Urgent Care who had so attentively listened to her cares and woes, yet shared none of her own.

Ms. Love re-learned something today that she wants to pass onto you. Because of reticence, fear, distraction or whatever you may find yourself dealing with, try not to stifle your or

another's chance for moments of intimacy, whether they happen in Urgent Care, on an airplane, or while walking your dog. Don't hold back. The things gone unsaid and undone may never get to be said and done again. I don't know Lydia's last name; I don't know if our paths will cross again. But Lydia, I am thinking of you and the gift of companionship you offered me. I am sorry it took your transfer to probably the Emergency Room for me to re-examine the value of precious intimate moments, even with people one may never cross paths with again. I won't forget. Be well, my waiting room companion.

*The Love and Intimacy Corner welcomes questions and requests for topic areas from readers. Please send all comments, questions and suggestions to Ms. Love at [DI.LoveandIntimacy@gmail.com](mailto:DI.LoveandIntimacy@gmail.com). Questions chosen to be featured in the Ms. Love column will appear under a pseudonym to protect privacy and may be edited.*

**REquipment Expands** - Continued from page 1

navigate the insurance process."

Stavros and UCP have been contracted as REquipment Reuse Centers, receiving funding to accept, refurbish and deliver donations of gently used wheelchairs (power and manual), scooters, shower chairs and other adaptive medical equipment. As a REquipment partner, these sites adhere to REquipment cleaning, repair and user support standards.

The addition of new reuse centers expands REquipment's current network to four regional Centers that clean, repair and deliver gently used medical equipment to MA residents. Donations can be dropped off in Boston at The Boston Home, in Canton at the Massachusetts Hospital School, and in Worcester at the flagship reuse center within the MA Department of Developmental Services AT Center. Users can find and request suitable equipment from all Centers by searching REquipment's web-based database at [www.dmeREquipment.org](http://www.dmeREquipment.org).

REquipment provides free gently-used, refurbished durable medical equipment to people with disabilities and seniors in Massachusetts. There is no charge for this refurbished equipment and delivery is available. REquipment accepts donations of gently used DME that are no longer needed and cleans, repairs and distributes them to people who cannot afford it or do not have adequate insurance. For more information, visit [www.dmeREquipment.org](http://www.dmeREquipment.org), [info@dmeREquipment.org](mailto:info@dmeREquipment.org) or call 1-866-244-6156.

*Randi Sargent is Program Director for REquipment, part of the MRC MassMATCH program.*



extra jellybeans, etc. The hard part was leaving that room and knowing I would not see that child ever gain.

Still, we get to be invited into a room during traumatic moments like this. The incredible part of our job is that we are invited into these moments because we are clowns. By assessing what is going on in the room, we help the energy shift. It is what we call a “shimmer” or “ripple effect” which brings peace, joy, magic and connection into the moment. We walk into clinic waiting rooms a lot and we often sense a heavy feeling in the room. We look into peoples’ eyes and can see the stress. But if we can make people smile and laugh, they feel less stress for a while.

Not everything is about a laugh. In the tougher scenarios, we acknowledge the patient’s humanity. We go into the patient’s room to connect. If a patient gets to boss us around for ten minutes, like one little girl did recently by telling us to, “Tell a joke, sing a song” that’s good because she gets to have control over something. We do our best to respect the space of patients and families.

We throw a lot of love at the kids while they are in the hospital. Clowns engage the heart of a child. We do not let the tubes, machines, etc. be a barrier against our engagement with a child. A terrible trauma or chronic condition may be happening, but we focus on what is good and the heart and spirit of a child.

Our job is to be present and engage with what is happening in the moment. We recently had a three-year-old child who had been bitten by an animal and had a big trauma on his face. When we knocked on the door, the mother’s face lit up. My clown partner and I tripped over each other trying to get in the door at the same time and the child started laughing. This grew into a deep belly laugh. The mother got out her cell phone and recorded her son’s laughter. When her son went into surgery the next day, the mother watched the video and felt comforted.



Photo: Dr. George Taylor, Boston Children’s Hospital.

**SN:** When you are not in clown dress, what do you do?

**Dr. MA:** Because of the nature and intensity of the work, none of us works more than three days per week. I volunteer with the Patient and Family Advisory Council at Beth Israel Deaconess Medical Center (BIDMC)-Boston. Healthcare is on the move and I see more focus on taking care of the whole person. At BIDMC, canine therapists are now coming into the hospital.

I also work as a theater actor. I write and produce for theater too. Right before this interview, I was painting a toy box for a show I’m doing in schools. Some of my fellow clowns in the Clown Care program teach circus arts, are magicians, musical theater artists, and more. All of them are professional performing artists.

*Sandy Alissa Novack, MBA, MSW, LICSW, ACSW, CSW-G, is a social worker who is on the editorial board of “Disability Issues” and is on the Beth Israel Deaconess Medical Center Universal Access Advisory Council.*

## THE PINEAPPLE PROJECT

In addition to Mal Malme’s clown role as Dr. Mal Adjusted, Mal is co-founder and actor in The Pineapple Project, a play for children about kids exploring gender issues. See [www.pineappleproject.org](http://www.pineappleproject.org) for more information, including an upcoming performance at Boston Children’s Museum on August 20. Mal is also a member of the cast of the New England premiere of The T Party, a play on gender expression in America today, at the Boston Center for the Arts, July 15-August 13, <https://companyone.org/production/the-t-party>.



“**Big Apple Circus** is committed to providing joy and wonder both inside and outside the tent. At Boston Children’s Hospital, our signature Clown Care program brings Clown Doctors to the bedside of hospitalized children five days a week. Sometimes, laughter really is the best medicine.

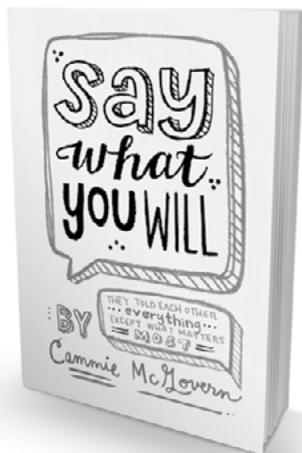
In addition to our regular performances in Boston, we also offer **Circus of the Senses** (performances for children and families with vision and hearing impairments) and **Big Apple Circus Embraces Autism** shows, which are adapted to the needs of special audiences.” — Will Weiss, Executive Director, Big Apple Circus

For more information about the Big Apple Circus and accessibility at their Big Top tent, visit [www.bigapplecircus.org/accessibility](http://www.bigapplecircus.org/accessibility), email the circus at [info@bigapplecircus.org.accessibility](mailto:info@bigapplecircus.org.accessibility), or call the Box Office toll-free at 1-800-922-3772.

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## Novels Portraying Young Adults with Disabilities

By Kate Ryan

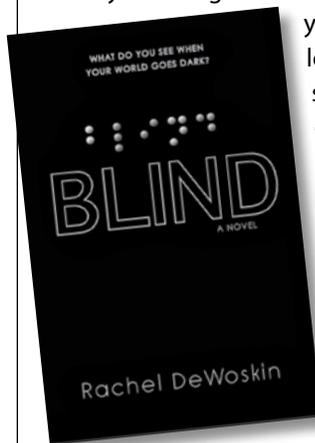


Looking for a new book to read? Two young adult novels about characters with disabilities are worth checking out. Both of them are notable for the simple reason that, unlike many novels about people with disabilities, the disability is not the entire plot.

*Say What You Will*, by Cammie McGovern, (HarperCollins, 2014) has one message for the world: disabled people have sex,

disabled teens have sex, and sex leads to very bad things. This is, apparently, a total revelation to many people outside the disability community, and McGovern weaves an interesting, albeit not entirely original tale around it. Even though the title character, Amy, is a rather tired disability trope – non-verbal person who is secretly a genius – she nonetheless comes off as an engaging, real character. Matthew, her love interest in the story, is also disabled by Obsessive Compulsive Disorder (OCD), and the book unfortunately follows the formula that when two ‘broken’ people fall in love, they somehow, magically, become whole and heal each other.

Amy, like many teenagers, struggles to define herself as both a person with a disability and one without a disability. This is not helped at all by the fact that in her world, the disability community is non-existent and almost all adults in her life are the patronizing, protective type, to the point where she hires ‘peer helpers’ to replace stodgy aides. Amy sees Matthew as a project to be fixed, and sets about doing just that. However, disability does not deserve such loathing as Amy gives it. A support or empowerment group, an on-line community or just an older mentor with a disability would have done a great deal to make this story more realistic and less saccharine.



Unlike McGovern, Rachel DeWoskin’s portrayal of the disability community in *Blind*, (Viking, 2014) is both positive, realistic and uplifting. The protagonist, Emma Sasha Silver, is your typical teenager dealing with an acquired disability, blindness, in a very honest manner. We meet Emma as she starts her sophomore year of high school, after having spent most of the past

year recovering from the accident that left her blind and attending Briarly, a school for blind students. The Briarly community is seen as key to Emma accepting her new self and coming to terms with her disability, thus exposing the reader to the sort of intimate details about living life while blind that the general public often wants to know about, but doesn’t want to ask. For example, how to organize clothes, how to cook, and how to learn cane skills. I also appreciated

the positive emphasis on Braille, which the majority of blind people today do not know but which Emma finds invaluable as she copes with both her new life and her old. The plot centers not just around Emma’s blindness, but also around the suicide of a fellow student at her mainstream high school, and how everyone has to deal with their own demons.

The journey that Emma, her family and friends, take in this book is told in breathtakingly beautiful prose, which is easy to read yet at the same time intelligent and insightful. “Truth isn’t always blinding, agonizingly sharp, cold, or bright.” Emma realizes at one point. (pg. 324-5.) Each word was a little lit bulb inside a night-light, leading me down a soft hallway in my mind.... “If I’m going to live with any of what’s happened to me, I have to remember everything as clearly as I can. Not banishing or forgetting or drowning any part of it.”

Emma Sasha Silver’s story is not one that you will want to banish or forget any time soon. It is instead the kind of book that stays with you for a long, long time, one that curls itself up inside you and leaves you feeling more whole than when you began.

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*Kate Ryan is a disability advocate. She has a master’s degree in disability studies from Lesley University and is a graduate of the Shriver Center’s Leadership Education and Neurodevelopmental and Related Disabilities (LEND) program.*

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## InfoBriefs InfoBriefs InfoBriefs InfoBriefs InfoBriefs InfoBriefs

### Accessible Voting Equipment

Both federal law and state requirements mandate that voting systems be equipped for voters with disabilities allowing such voters to have the same opportunity to vote privately and independently. It is required that every precinct must have at least one accessible voting machine available.

There is at least one accessible marking unit in every polling place in Massachusetts. The AutoMARK® Voter Assist Terminals are marking devices that use audio cue capacity for visually impaired voters. The AutoMark also has a feature that will greatly magnify the ballot or display the ballot high-contrast for voters that have limited visual impairment. The AutoMARK® can also produce an oral report to the voter as the choices selected prior to the voter printing the ballot.

For more information on the AutoMARK® Voter Assist Terminal, please visit [www.essvote.com/products](http://www.essvote.com/products) and select "Ballot-Marking Devices" from the menu.

The Elections Division of the Secretary of the Commonwealth of Massachusetts is committed to making voting as accessible for all voters. Please let us know how we can improve accessibility by calling us at 800-462-VOTE (8683) (toll free) or 617-727-2828. You may also e-mail us at [elections@sec.state.ma.us](mailto:elections@sec.state.ma.us).

### Discovery Museums: Accessible for All



The Discovery Museums in Acton broke ground last fall for a \$1.5 million project to develop a fully inclusive nature play space for children and families called "Discovery Woods", expected to open this summer. The central feature will be an accessible tree house and learning center where those with mobility, development or behavior differences will find elements of adventure and discovery alongside other visitors. [www.discoverymuseums.org](http://www.discoverymuseums.org)

