

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.

Volume 38 • No. 2

Spring 2018



Braille Literacy: One man's life-long experience

An interview by Helen Kobek
with Carl Smith, a.k.a. DJ Castrawdis

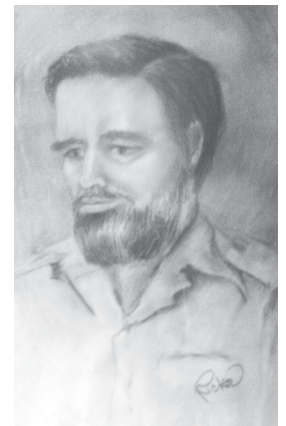
Carl Smith, a talented, young DJ from Boston, Massachusetts, is ready for his DJing career. He is focused. He has learned his art and continues his education about it. He is vibrant, funny, expressive, and he likes good conversation, as any dedicated DJ would. And... he is blind...and HE KNOWS BRAILLE. Carl knows that his braille literacy is essential to his career. And, while braille tends to be perceived as a mix of "cool" and "mysterious" to the sighted world, it's both necessary and no-mystery to braille-literate blind folks. Helen Kobek interviewed Carl, a.k.a. DJ Castrawdis,

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The Special People In Our Lives

By Joan Burrows

How different life would be if it weren't for the special people that come into our lives. I can remember the special people in mine, but the most special was Walter, my partner of over twenty years. Walter had Muscular Dystrophy and circumstances left him in his room – a room he could not walk from – for over 10 years.



A doctor was the first special person to come into his life during this time. He tended to him physically and then stayed and talked with him for a long time. He returned several times and finally convinced Walter to get evaluated at a hospital for a wheelchair because he needed to get out in the world. He saw that Walter had much to contribute.

The next special person was a social worker who came into his hospital room in her wheelchair. She told him about her job, how her life changed after an accident, and help was available for him. Before that, Walter did not try to get up and use a wheelchair because no one had given him hope. He often said, they "bounced in and out of his room in their short skirts and heels." This young social worker was different; she convinced him to try. She came back on the day he used an electric wheelchair for the first time. Soon they were racing in the halls. She continued to help Walter by contacting organizations where he could get the help he needed. They remained friends. The day arrived when Walter came home. The door to his room was widened, a ramp was finally put in, and plans were made for Walter to go out and be with other people. Walter loved people and he had been cut off for too many years.

Next, Walter met me! He came into the Cooperative Elder Services, a day center where I was doing an internship for a social work degree. I was getting this degree later in life and Walter was interested in going back to school so we talked often.

I connected Walter with the next special person in his life who worked at the local college. I arranged an appointment for them to meet. The meeting went perfectly and plans were made for Walter to take two courses. He decided to take the classes in

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A B C D E F G H I J

The Right to Read: The Struggle for Braille Literacy*

By Helen Kobek

Louis Braille was three years old when he became blind by an accidental injury in 1812. He became educated, and created what is now known around the world as braille—the raised dot system of reading and writing used by blind, vision impaired and some individuals with dyslexia. (Going forward, for brevity, the writer will refer to this group of people collectively as “blind.”) Louis Braille, himself, went through many struggles to bring forward this system so the blind may read. At the institution where he was developing and disseminating braille, braille books were burned and braille embossing tools were confiscated by the academic officials who felt threatened by the independence of blind people. But punishments for using, reading, producing, and teaching braille—which included being beaten and deprived of food—were ineffective at deterring students from reading braille and teaching it to one another. Knitting needles were smuggled into the school and secretly used to produce this most vital system of reading and writing.

This rebellion reflects the strength of the drive for literacy. Today, braille is still a lifeline and a source of liberation for those of us who rely on it for efficient, comfortable, accurate access to written matter. If you are reading this and you are a print reader, imagine all the things you read with your eyes all day. Imagine that access being taken from you, and you can begin to imagine the struggle for literacy braille users still face.

Less than 10% of blind children and adults in the United States can read braille. Speech-to-text technology has been replacing the use of—and perceived need for—braille for the past 15 years. Text-to-speech technology has its uses for blind computer users, but speech production of the written word is not adequate for our literacy. Here is why:

1. There is no easy clarity of spelling. As one reads with text-to-speech, the words are spoken, not spelled, unless you set it to read letter by letter. This is quite tedious. Many blind people who are not braille literate do not know how to spell. This makes it challenging for us to compete in the workforce, and is often socially awkward in the letter-writing and emailing realms. Learning English (either as children or as adult learners) with text-to-speech makes it difficult to learn sentence structure. Blind people need to have access to spelling and composition, and this can only be truly accessed through braille.
2. We must listen to someone else’s (or a synthesized) voice. This can be anywhere from tiresome to mind numbing. Non-print readers, just like print readers, often enjoy the silence of our own minds when reading.

3. Moving fluidly around on a page of text is nearly impossible with text-to-speech. Skimming is out of the question, and demarcating one’s location is challenging. Text-to-speech in these applications limits and de-skills us.
4. Reading numbers—e.g., keeping track of our finances—is much more challenging using text-to-speech. And turning personal financial matters over to a human reader is painful, if not dangerous. Braille gives us dignity and privacy.
5. Humans use a different part of the brain when reading. That part of the brain is not used when we are simply listening. We do not process information in the same way when listening. Not sure you believe this? Ask yourself these questions when you are having a conversation: 1. Am I reading what they are saying or am I listening? 2. How would I attend differently if I were reading what they were saying? When people read braille, the same part of the brain is used as is used when reading print. That part of the brain is dormant when listening. For this reason, many braille readers, when taking in a recorded book, for example, say they are listening to, rather than reading, a book.

In addition to the limitations of text-to-speech, braille literacy is necessary for getting around in the world. Braille is used in public areas. It is in bus stops, airports, medical buildings, and it labels bathrooms by gender. This prevalence allows blind people to travel with ease, independence and dignity. Without braille, we can seem awkward, inept, dependent, and even stupid. (In case you’re wondering how a blind person finds the sign next to the bathroom: Accessibility regulations direct that braille signs be placed on the latch of the side a single door.)

Literacy is a basic element of liberation in our written-language culture. Without being able to read, we cannot work, travel competently, or maintain certain aspects of social relationships. (70% of blind people are unemployed, and, of the 30% who are employed, 90% know braille.) We are significantly marginalized. Let us strive to move blind, vision impaired and other print-disabled individuals out of the margins, and directly onto the middle of the page—where the dignity, respect—and the words—are found.

* Reprinted and modified from original printing in *Cradle of Liberty News*, June - July, 2013

Helen Kobek has been low-vision since birth and a disability advocate since college. She is an Accent Modification Instructor and author of “Everyday Cruelty: How to Deal with Its Effects without Denial, Bitterness, or Despair.” For more information about Helen, visit helenkobek.com.

Disability Issues is a publication of Spaulding Rehabilitation Network, a member of Partners HealthCare. The Spaulding Rehabilitation Network includes Spaulding Rehabilitation Hospital, its main campus in Charlestown, which is a national model for environmental and inclusive design as well as Spaulding Rehabilitation Hospital Cape Cod, Spaulding Hospital Cambridge and two skilled nursing facilities, as well as twenty-five outpatient sites throughout Eastern Massachusetts. Spaulding strives to continually update and improve its programs to offer patients the latest, high-quality care through its leading, expert providers. Spaulding has been awarded a Model Systems designation in three specialty areas- Brain Injury, Burn Injury Rehabilitation, and Spinal Cord Injury - by the National Institute on Disability, Independent Living, and Rehabilitation Research. Spaulding is a teaching hospital of Harvard Medical School as well as the official rehabilitation hospital of the New England Revolution. Spaulding is the only rehabilitation hospital in New England continually ranked since 1995 by *U.S. News and World Report* in its *Best Hospitals* survey with a #4 ranking in 2017-2018. For more information, please visit www.spauldingrehab.org.

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From the Editor

Dear Readers,

In this issue, we bring you articles about various types of disability-related relationship and communication experiences. Being in relationship with others, and being in relationship with our own disability, creates unique complexities as we move through the world – some positive, and some challenging.

One of my complex disability-related challenges is my relationship with using crutches and how I'm perceived by others. I was born with Spina Bifida and have walked with crutches all my life. Like many people who use mobility or medical devices, when children see me, they stop dead in their tracks and stare. Over the years, I've had many reactions to children staring at me. Sometimes I just stare back at them – hard – until they get uncomfortable and look away. Sometimes I put a big smile on my face to try and convince them I'm not scary.

Kids staring is challenging. Logically, I know it's human nature to notice something "different." In this case, my crutches and the way I walk. And yet, I still feel a stab of pain because I'm "different", and what I've wanted more than anything most of my life is to be "normal" and fit in. It's taken many years of therapy for me to realize there's no such thing as "normal" and to be more comfortable accepting my disability as part of who I am. I've noticed, the more I accept my disability, the less upset I feel about kids staring, and the more I'm okay with their natural curiosity.

Now, when kids stare, I am more likely to smile and say "Hi." Depending on my mood and how much time I have, I either continue on my way or I ask if they're looking at my crutches. If the child nods their head "yes," I say, "I use crutches to help me walk because some of the muscles in my legs are weak." That satisfies most of them; only occasionally do I meet a chatty kid who has more questions.

I'm very aware that it's not my responsibility to educate children (or adults) about my disability, but I do feel like I have an opportunity to make a connection with children. My hope is, each child I make a positive connection with will be less likely to stare at the next person they meet who has a disability.

Marianne DiBlasi, Editor



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Love Letters

by Ms. Love

Anyone who has ever received a love letter in the mail knows a letter will never be replaced by email, tweets, Facebook, or anything else. The feel of the paper, the smell of your beloved's perfume, the enclosed dried flower keepsake, the thrill of seeing your beloved's handwriting, there is just nothing like a real love letter.

But you do not have to take my word for it: Twenty-five of artist Frida Kahlo's love letters sold for \$137,000 at auction in 2015. Frida had met artist Jose Bartoli in the United States while recuperating from spinal surgery, and their relationship continued even when she returned to Mexico and to her husband. Here is an excerpt, "...Since I fell in love with you everything is transformed and full of beauty...love is like an aroma, like a current, like rain. You know, my sky, you rain on me and I, like the earth, receive you" (www.doyle.com/auctions).

Joan Burrows is another recipient of love letters. *Disability Issues* is happy to welcome Joan as a new Editorial Board member and she was happy to be interviewed about love letters with her partner Walter.

Ms. Love (ML):
Please tell us about Walter.

Joan Burrows (JB): When I met Walter, he was a man in his late 50s. He had Muscular Dystrophy, used an electric wheelchair, and had recently started attending a day center. Before the day center, Walter had been in his bedroom for over eight years, unable to get out of bed – first with his son caring for him, then his daughter, and then home health aides.

Walter graduated from college when he was in his 60s. He also was a key player in the beginning of the Commission on Disabilities in Acton, MA.

ML: When did the letter writing start?

JB: We became close shortly after we met. Walter began by writing a note to me while he was waiting for his ride to the day center. I would read it when I came by in the evening. I did not write a lot then, as I was busy with piano teaching, being with my children, and so on. The notes continued on and off after we moved in together, but only when we were apart. For example, he wrote letters when he was hospitalized or sometimes when I was out of the house seeing my children. In 1999, Walter no

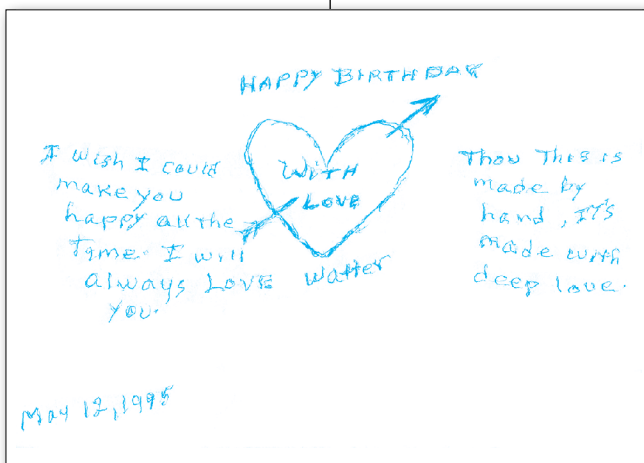
longer had the strength to use a pencil, so the letters stopped. Walter found a creative way to communicate; he began writing with his finger! It started when Walter woke up from a coma and found himself intubated. He wanted to communicate so he used his finger as a pencil; writing letters on the sheet of the bed. Just his finger. The nurses were amazed.

When Walter was transferred to Boston, he got a trach, and remained on a ventilator. He was finally transferred to a rehabilitation facility and was once again able to write notes using a pencil. In one note, he wrote:

*Darling,
I am not sure I am going to make it out of here. Today the nurse spilled water while washing my hair and short-circuited the vent. Maintenance had to come and she bagged me while they fixed it. I don't know how we can manage at home.*

*I love you,
Walter*

I have a beautiful birthday card from 1995 where he drew a heart and wrote a note. He always wrote notes in the cards he gave me. For every birthday there were two cards – a loving one and a humorous one! But, Walter didn't just wait for special occasions to write notes. He wrote anytime he wanted to share what was in his heart.



ML: Would you like to share more letters with our readers?

JB:
*Hi Honey,
It is really hard to go through the day without you...I wish we could be together all the time. Do you think we can really buy a van of our own? It is almost too much to hope for. I know you are talking with Massachusetts Rehabilitation Center and working on it. Our walks have been so good, and we watch the cars go by on the highway. Oh, how great if we were one of them. "On the Road Again."
All my love,
Walter*

Walter loved Willie Nelson and the song "On the Road Again."



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Love Letters - Continued from page 4

About nine years later, Walter had aspiration pneumonia. A "Do Not Resuscitate" order was signed. Then the decision had to be made about a feeding tube, or he would not survive. I wrote this:

Dearest Walter,

The decision you have to make is yours alone, but I want you to know that I love you with all my heart and I want to have more time with you – we have more fun things to do. We can get through anything together – we already have – think of all we have done. If you cannot eat, we can still take trips, and sit and talk, and watch movies...and make love.

*I love you so very much,
Joan*

The letters are stored in a shoebox marked "personal." The shoebox was not decorated; the letters in the box made it a beautiful box of love without anything else needed. Every time I took the

letters out to re-read them, I thinned them out a little at a time. It was hard. Several years ago, I spent a week in the hospital and when I was home recuperating I did a major thinning. I didn't think my children needed to read them. I still have a few letters left; it's hard to let them go, but the memories are clear and the love is strong.

ML: What makes a good love letter?

JB: Just written from the heart. At the time, I don't think we thought of them as "love letters." They were just one the many ways we communicated with each other.

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. Questions chosen to be featured in the Ms. Love column will appear under a pseudonym to protect privacy, and may be edited.

Special People... - Continued from page 1



a cubicle at a learning center because he was hesitant to go into a classroom. He aced both courses and went on to take more classes and earn a degree. He accomplished a lot during his time there; one was setting up and helping run a Disability Awareness Day for the college. He made friends with a professor and they met socially.

From there, Walter and I made a life together and worked to help make the world a better place for many special people

with disabilities. We worked on access and attitudes in the town, with the schools, and then we began the Acton Commission on Disability where we met many people who became friends.

Other special people in Walter's life were his Personal Care Attendants who allowed him to live at home. PCAs are truly special. They get paid very little and are expected to be on the job when it snows, on holidays, and even when they're not feeling well. Without them, the person may not be able to

get out of bed, eat, or have their basic needs tended to. PCAs allow people to get out of the house and go shopping, eat out at restaurants, travel, work, volunteer...and more. PCAs are people of all ages from teens to seniors – female and male. They are as close to angels as one could be! Without them, Walter could not have accomplished all he did for others.

How different his life, and the lives of others would have been, without all of these special people. Walter is my special person... he changed me. He has given me something to work on in my retirement – helping people by working with the Commission on Disability in Acton. The Commission just celebrated the 30th anniversary – the anniversary of when Walter and I started the Commission.

Walter died in December 2001. He used a respirator for many years and later, a feeding tube. He kept his sense of humor through everything and I miss him – the most special person in my life.

Joan Burrows studied music in NYC and later taught piano. She was a nursery school owner, teacher, and music director. Joan began the Acton Commission on Disability with Walter Kiver. She is a caregiver for people with disabilities and seniors.

Adaptive Communications and Your PCA

By Ray Glazier

In the Spring 2015 issue, I wrote the article *Tips for talking with Your PCA*. But in the spirit of this issue's theme, I shall discuss communication augmentation from a very personal perspective. You see, I have a speech impairment from the brain injury that made me a wheelchair user and a PCA services consumer. My hearing is no longer that great either.

I have a palate prosthesis (or obturator), fitted similarly to a partial denture, that improves my articulation by raising my soft palate to cut down on nasality. My PCAs can tell immediately when I forget to put it in. My other speech augmentation device is a body-worn microphone & speaker box system that helps compensate for the softness and low volume of my impaired speech. This setup is designed for, and mainly used by tour guides to amplify their narration for group tours in parks or museums, as well as by classroom lecturers and by elementary school teachers trying to maintain a semblance of order on the playground at recess. Likewise, my PCAs will remind me when I forget to wear it or absent-mindedly forget to turn it on, as happened once in an important university faculty meeting.

But these adaptive devices do not always do the job in certain situations. Years ago, I had a live-in PCA who was profoundly Deaf without his two hearing aids. Face-to-face he and I usually managed, with our respective devices, to communicate satisfactorily at a basic, rather rudimentary level, sometimes aided by hand gestures. (If you hire a Deaf CA, take some online instruction in sign language; be aware that persons from other countries may use sign language different from the American Sign Language or ASL.) But neither of us employed our devices once we turned in for the night. So, if I needed Brian's help after

lights out, I was out of luck. ("Help! My legs just spasmed off the edge of the bed.") Now I just use my cellphone to text upstairs for needed help at 2:00 am.

Cell phones are great, but I only text on mine; I don't try to talk, because no one can hear or understand my vocalizations. The upsides: a) I only need a cheap old Dumb phone for that, and b) Because everyone knows I never pick up calls, only telemarketers call me on my cellphone, and they never get to me. What is beginning to get to me is the perky prerecorded voices, usually female, who want me to tell them the reason I am calling their help line. Even with my amplified landline phone, they can't hear or understand. So, before they hang up on me, I press 'Operator' repeatedly. Sometimes that gets me through to a live human being. And, if that fails, there's usually an on-line chat option. Even though language skills of the chat operator replying from Bangladesh or the Philippines may be less polished than the synthetic voices on help lines, at least it is a real person with whom I can reason.

But more and more electronic devices (and maybe the robotic PCA of the future) come equipped with AI systems like Alexa, Android, and Google Assistant. With these voice recognition systems, I am back to my starting point 20 years ago. I can only hope they are eventually able to learn to understand me, as my current PCAs have. Bless their hearts (and ears)!

Raymond E. Glazier, Ph.D. is a longtime MassHealth PCA Program consumer who has studied PCA issues for decades. He is currently founder and Principal of disAbility Research Associates in Belmont, MA. Contact Ray at ray_glazier@post.harvard.edu with questions, comments, or suggestions for future columns.

The Bookshelf



Book Review:

The Golden Age

Reviewed by Mary Grimley-Mason

The Golden Age, a novel published in 2016 by the award winning Australian author, Joan London, is set in a polio convalescent home in Perth, Australia. At age twelve, Frank Gold comes with his parents from Budapest, Hungary to escape the Nazi occupation and its destruction to their lives. They arrive in the middle of a polio epidemic (before the Salk vaccine) and Frank is infected and placed in *The Golden Age*, a remarkably caring children's polio hospital that actually existed in Perth in the 1940's and 50's.

This is a love story about Frank and a young patient, Elsa, and

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about his lived experience with learning and using braille. Here's what he has to say about braille's importance in his life:

Helen Kobek (HK): When did you learn braille?

DJ Castrawdis (DJ): Age three to four. I had braille teachers who used something called "swing cells" to teach me.

HK: What was it like to learn braille?

DJ: To tell you the truth, it was not a big deal then because I didn't understand that I would be using braille for the rest of my life. I was only three years old. I didn't get it until early elementary school. As I moved from grade 1 braille through grade 2 braille (contracted braille), it sunk in. My braille teachers said, "You don't get it now, but you'll be using this for the rest of your life and it will matter to you." They told me to take advantage of braille whenever it's available. And I have.

HK: Are you glad you know braille?

DJ: Yeah. Really glad.

HK: How would your life be different if you didn't know braille?

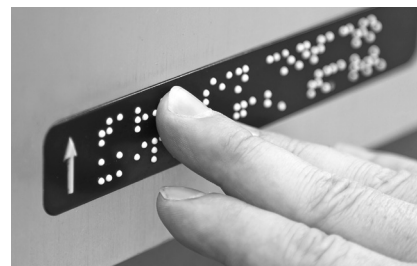
DJ: It would be more complicated. I'd be much less independent. I'd have to ask five million people, "Can you read this for me?"

HK: What do sighted people need to know about braille?

DJ: Sighted people ask me how I read and write. I tell them I use braille. They say, "What's that?" Most sighted people do not know about braille. This is a problem because they can't advocate for something they do not know exists or is needed. Braille is complicated to sighted people, but straightforward to us. And it's this simple: Sighted people use print. We use braille. Print is the system of literacy for sighted people. Braille is our system.

HK: Do you feel sighted people care about our learning braille?

DJ: Initially people seem interested, then it becomes clear that our literacy doesn't matter to them at all. They think we can get people to read things to us. They need to learn that our independence matters.



HK: Should sighted people have the opportunity to learn braille by sight?

DJ: Absolutely! It's one of the basic things all people should know.

HK: What do you think is the perception of braille by the blind?

DJ: If we're in the know, we know we need it. But it's one part of our independence. Many of us aren't independent even if we know braille. It's not a cure-all. It's just how we read.

HK: Do you feel braille is beautiful?

DJ: I don't personify braille. Sighted people already have enough trouble understanding braille without giving it a personal characteristic. Braille is ordinary. Ordinary, but without it, we're in trouble.

Helen Kobek has been low-vision since birth and a disability advocate since college. She is an Accent Modification Instructor and author of "Everyday Cruelty: How to Deal with Its Effects without Denial, Bitterness, or Despair."

For more information about Helen, visit helenkobek.com.

InfoBriefs InfoBriefs InfoBriefs InfoBriefs InfoBriefs InfoBriefs



MBTA's The RIDE Partners with Lyft and Uber



You may be familiar with using MBTA's The RIDE as an option to get out and about—and you also may be familiar with the fact that the program has struggled to provide on-time service for customers, especially in recent months.

Looking for a more creative solution to these paratransit woes, the MBTA partnered with Lyft and Uber for a pilot program last fall. The program was so successful that it is now available to anyone who is eligible to use The RIDE services.

What are the key differences? Rather than booking The RIDE a day in advance, customers can now request rides almost immediately—no planning ahead! And the cost per trip is also

lower. For every trip with Lyft or Uber, you'll pay the first \$2 and anything over a \$42 fare, making the average for a trip with Lyft/Uber only \$4.38. Conversely, the average cost for The RIDE is \$5.25. Wheelchair accessible vehicles are available on both platforms from 5 a.m. to 1 a.m., and companions (family, caregivers, and loved ones) can come along for the trips with Lyft and Uber, too.

Though Lyft and Uber are most often requested via smartphone, riders will also have a call-in option via Lyft Concierge. Uber, on the other hand, will be providing a limited number of free smartphones for customers. You may request one at the time of registration.

For more information, including information about rates and how to sign up for Lyft or Uber, visit www.mbta.com. In the search field, enter "On-Demand Paratransit Pilot Program."

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how they share each other's slow recuperation and become soul mates. Frank, a survivor of the horrors of war, is more sophisticated and skeptical about the world in contrast to Elsa, who is a native of Perth and has grown up in a simple but nurturing family and is used to caring for others. The love of the two young people becomes innocent passion which is unacceptable to the rigid morality of the Board members at The Golden Age. They are both expelled and return to their families.

This story is also about adapting to a different culture. Frank's parents, as educated cultural Europeans, find it difficult to adjust to "the new world" of western Australia. Ida Gold, a former concert pianist, feels particularly alienated in the simpler life of her new home. She does her best to adapt and even gives a concert for the children and their families although she had vowed never to play or perform again. Her husband, Meyer, however, connects more easily with his environment, finding beauty and naturalness in the people and in the rural and coastal landscape.

The two young people, Frank and Elsa, are also challenged to find a place in a different culture, that of the able-bodied world. After their expulsion from the clinic, we see the two of them struggling to adjust to their limitations. They see each other only one more time as arranged by their parents. Although they

find themselves still bound to each other, they realize their lives will take completely different directions. The story then moves, perhaps too sharply, to years later when we learn how each of them has found a vocation. Frank has pursued an intellectual role and has become a well-known poet. Elsa is a doctor and has married and has three children, one of whom will meet Frank, suggesting that the connection and bond forged between the two young people in the past will remain.

In her novel, Joan London has told a story using disability without pathos or sentimentality. The clinic is a safe and happy place for the children struck by polio, but London does not ignore the sad and often tragic circumstances of these children and their families. By placing Frank and Elsa's story in the context of the larger theme of displacement and recovery – both cultural and physical – she develops a story on the theme of human resilience.

Mary G. Mason is a PhD Professor of English emerita, Resident Scholar, Brandeis University's Women's Studies Research Center, and author of; "Life Prints: A Memoir of Healing and Discovery," "Working Against Odds: Stories of Disabled Women's Work Lives," and "Taking Care: Lessons from Mothers with Disabilities."