***Disability Issues***

**Vol. 44, No. 2**

**Fall 2024 – We’re Back!**

*Providing individuals with disabilities, their families, friends, and advocates with relevant information to enhance their quality of life, health, and employability options.*

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*Disability Issues* is also available on audio and in large print through Perkins Braille & Talking Book Library. To receive either of these special formats, contact the Perkins Library by calling toll-free 1-800-852-3133 or 617-972-7240 or e-mail Erin Fragola, Outreach Manager, at Erin.Fragola@Perkins.org or visit [PerkinsLibrary.org](https://www.perkins.org/library/).

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**Table of Contents:**

From the Editor |  Marianne DiBlasi
*Disability Issues:* A Publication Worth Saving! |  Kim Charlson
Reading Never Sounded So Good... | Perkins Library
Climate Change and Heat |  Sandy Alissa Novack
Aging with a Disability |  Penelope Ann Shaw
Caring for Each Other |  Joan Burrows
As if They Didn't Exist, As if None Died Before Their Time... | Margaret Morganroth Gullette
Love & Intimacy Corner: Ella: An Inclusive Fairy Tale | Ms. Love
Info Briefs:
• Kim Charlson, Perkins Library Executive Director, Receives Highest Honor in Field of Blindness
• Mattel Launches New Barbie Dolls with Disabilities
• National Disability Employment Awareness Month Event

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**From the Editor:**

Dear Readers,

Wonderful news – *Disability Issues* is back! The editorial board and I are thrilled to resume publishing this newsletter, which is dedicated to providing valuable content for the disability community and their allies. A huge thank you to all our readers who reached out to express your appreciation and support after so many years of enjoying *Disability Issues*. Your belief in our ability to find a way forward was a powerful force and, guess what? It worked!

Just days after our farewell issue, I received an email from Kim Charlson, Executive Director of the Perkins Braille & Talking Book Library in Watertown, who suggested we have a conversation to explore possibilities. You can imagine how quickly I responded! In the next piece, Kim shares what motivated her to provide partial funding for two issues, making it possible for us to bring you this issue of *Disability Issues*. Kim, we thank you and Perkins Library for your generous support!

We invite one or two more partners to join the Perkins Library in supporting *Disability Issues* as a financial sponsor. Together, we can continue bringing the disability community four inspiring issues a year! If you’re interested in having a conversation to explore how we can collaborate, I’d be happy to talk with you. Please feel free to reach out to me at disabilityissues@disabilityvisibility.com. I look forward to connecting with you!

In celebration of our exciting new partnership with Perkins Library and in honor of National Disability Employment Awareness Month this October, we’re featuring an inclusive fairy tale written by Ms. Love. The story centers around a main character who is blind and receives meager wages for her work. This issue also brings you a series of thought-provoking articles related to aging, the impact of COVID on older adults in nursing facilities, and a piece inspired by this summer's sweltering, muggy heat. Remember that? Hard to forget!

Be sure to check out the Info Briefs at the end of this issue, where you’ll discover why Kim Charlson was honored with the prestigious 2024 Migel Medal – the highest award in the field of blindness – along with other exciting and important updates.

Thank you, dear readers, for your loyal readership and for continuing to be part of our journey. We are so happy to have you with us as we move into this exciting new chapter!

With heartfelt gratitude, Marianne DiBlasi, Editor

*Marianne DiBlasi has been the editor of Disability Issues since 2011.  She was born with Spina Bifida and uses a combination of crutches and wheelchair to assist with mobility.  Her background is in sales and marketing, program management, and disability inclusion training.*

***Disability Issues*: A Publication Worth Saving!**

**By Kim Charlson**

Almost since the beginning of Disability Issues and its predecessor Together, the Perkins Braille & Talking Book Library has been making it available in an audio format by narrating it in our recording studio for blind and print-disabled individuals. We have also distributed a large print edition to our low-vision borrowers.

When I read the farewell announcement in the summer issue of Disability Issues, I was surprised, sad, regretful, and already missing its numerous contributions. I said to myself, “Something needs to be done!”

I never like to see a useful, valued publication disappear, so I took a step back and asked myself, “Is there anything I can do to help save Disability Issues?” It was so important to me that I decided to reach out to Disability Issues editor, Marianne DiBlasi, to learn more about the production process and the expenses involved. I asked what it would take to keep Disability Issues around for people who rely on its information, and Marianne indicated that it would cost between $16,000 and $20,000 annually.

That may sound like a big number, but I didn’t look at it that way. I thought, is that all it takes to keep such a well-written, professionally produced disability publication around for our community? I am willing to do something and make this happen. So, the Perkins Braille & Talking Book Library is now supporting roughly 50% of the annual production expenses for Disability Issues. We are searching for other partners to keep this valuable resource going, and there are some good possibilities on the horizon. For now, this issue and the next issue are covered by the Perkins Library, and we hope to have more good news about other partners in our next issue.

**Partners truly make a difference!** If your organization is excited about the possibility of being a co-sponsor of *Disability Issues*, I encourage you to reach out to our editor, Marianne DiBlasi, to explore the opportunities together.

The more hands we have, the stronger and more vibrant this publication will be as we move forward. Together, with valued partners, we can ensure a bright future for *Disability Issues*. Let’s make it happen!

*Kim Charlson is Executive Director of the Perkins Library, a division of international NGO Perkins School for the Blind.  She was the first female president of the American Council of the Blind (2013-2019) and was selected by the Board of Trustees and leadership for the American Foundation for the Blind (AFB) to receive the 2024 Migel Medal.*

**Reading Never Sounded So Good…**

**By Perkins Library**

The Perkins Library is a free accessible public library for people who have difficulty reading traditional-sized print. This includes people who are blind, have low vision, are physically unable to hold a book, or have a reading or learning disability. Affiliated with the Library of Congress, the Perkins Library works in collaboration with the National Library Service for the Blind and Print Disabled (NLS) and serves residents of the Commonwealth of Massachusetts with accessible and completely free materials shipped right to your door. While many people only associate Perkins with vision loss it is important to know that many more people qualify for this service. Perhaps someone has 20/20 vision, but they are unable to process print, thus making the book inaccessible. A person may be eligible for services if they have severe arthritis, Parkinson’s Disease, paralysis, or any other condition that makes it difficult to hold a book or turn pages.

Eligible people can apply to become a borrower of the Perkins Library by submitting a simple application. The application needs to be signed by a certifying authority such as a doctor, social worker, activities director, or professionals in the medical and human service arena. Patrons can then choose to have books sent to them based on their reading interests automatically or simply request titles over the phone or online. Some patrons get one book a month; others get ten books a week. The choice is theirs. Best of all: Everything is free!

* Perkins audio books and magazines are delivered by mail via a door-to-door service -- no postage is required.
* Easy-to-use playback equipment is loaned to the patron, free-of-charge.
* The Library has access to over 150,000 audio books, 25,000 braille books, and 15,000 books in Large Print.
* Newspapers and magazines can be listened to over the phone or online; with the television schedule also being available.
* Audio and braille materials can be downloaded at any time of the day or night.

Like many public libraries, Perkins loans movies on DVD and Blu-Ray. All movies from Perkins have a separate soundtrack where a narrator describes key visual elements of the film so that a person with vision loss is not left guessing. The narrator never speaks over the dialogue but between it. Captioning is also included.

A loyal patron reflecting on almost fifty years of using these services offered the following, “*Talking Books have probably been the single most important influence on my entire life. Some people say we are what we eat; I think we are what we read.*”

To become a borrower of the Perkins Library or for more information about these and our other free services please contact our Outreach Manager Erin Fragola by emailing Erin.Fragola@Perkins.org or calling toll-free 1-800-852-3133 or 617-972-7240.

**Climate Change and Heat**

**By Sandy Alissa Novack**

As I write this in August, I am hot! But I think I am lucky in that my current apartment has more air flow than my first apartment decades ago, a tiny studio in Boston where I had no air conditioning, and the windows faced a courtyard where the next building was only a few feet away. There were no trees for shade and no chance of a breeze.

I keep memories of that hot apartment front and center in my mind when I now advocate for heat protection for others during noticeable climate change.

A few years ago, people in the disability community came together with a local independent living center to discuss how to address the needs of many people in the disability community who do not have air conditioning or cannot afford to run it for the number of hours needed to cool down their homes. We originally thought about getting some air conditioners donated for people most in need. However, due to climate change, each year the situation gets worse with higher temperatures during the day and minimal cooling off at night. Heat emergencies are killing more people each year; more than the number of people killed by hurricanes, tornadoes, and other disasters.

Last year, I was part of a small group of participants at Dignity Alliance Massachusetts (DAM) who met with managers at the Massachusetts Executive Office of Health and Human Services to voice our concerns for policies on climate change and heat. We discussed the fact that the state offers a way for some people to apply for assistance to pay for heating in the winter, but there is no comparable help in the summer for the cost of cooling. So, even though some people may have an air conditioner in their home, they avoid putting it on because it costs too much for their budgets. Also, we brought up that it isn't life preservation for anyone who needs utility help if they must hope for assistance so they can afford the cost of utilities. DAM advocated that anyone who is eligible for help with heating in the winter or needs help paying for air conditioning in the summer, should be entitled to assistance, not just a portion of those who apply more quickly than others. We expressed concern about power shut offs if people with disabilities and elders cannot afford their utility bills. We asked if protections could be put in place to prevent shutting off utilities during the extreme heat of the summer, like in the extreme cold of winter.

We spoke about the needs of the most vulnerable during power outages, such as those who need power for their wheelchairs, C-PAP machines, ventilators, and power for refrigerators to keep medications cold. We must make sure we keep our power grids as robust as possible to reduce the risk of losing power during heat emergencies. We spoke about the many vulnerable people in the disability community during heat emergencies, such as those with respiratory conditions, schizophrenia, and other conditions. We spoke about long-term care facilities who have residential units with no air conditioners and windows that cannot be opened for ventilation or a cooling breeze.

What about people with disabilities who depend on providers for their care? Homemakers, home health aides, visiting nurses, physical therapists, and others who travel in the heat; sometimes from subway to bus to walking with heat zapping their strength and breath? What kind of heat policies do their employers have in place to guard their health?

Let your lived experience and imagination guide you on what else we need to consider and actions we need to take around climate change and heat emergencies. For example, some cities in the United States are considering passing regulations that landlords must provide air conditioning, just like they must provide heat. Some people think insurance companies should be responsible for providing air conditioners to their patients whose health is impacted by extreme heat. In the short-term, that could be a big expense for insurers, but in the long-term they would save money if the person is kept out of the hospital and does not need on-going medical care for heat-related health issues.

In some parts of the country, cities and towns are planting more trees for shade to cool neighborhoods, while others are experimenting with new roofing material to lower the heat of buildings. Still others are concerned about the number of people who get dehydrated and fall on extremely hot sidewalks, resulting in severe burns and hospitalization. Some areas are considering using new materials for sidewalks that won't get as hot from the beating sun.

Climate change and food supply must also be on our radar. Flooding can wipe out a farmers’ crop and prolonged hot dry spells can decrease crop yields, resulting in less fresh produce for communities. To address food insecurity, the Grist article by Frida Garza listed in the related resources section indicates that food pantries and meals-on-wheels organizations are taking on a new role during climate emergencies.

A lot needs to happen in this world of ours to help us all thrive with climate change. Add your voice and your vision for what can be done. Connect with online climate change groups or tell your local independent living center you want to help address climate change issues for people with disabilities. Stay up to date on climate change issues by subscribing to websites like [Grist](https://grist.org/) who publish articles about climate solutions. Tell your legislators that you depend on them to keep the needs of people with disabilities and elders front and center in the communities they serve. Ask them what they are doing about addressing the needs of the most vulnerable during heat and other climate related emergencies.

*Sandy Alissa Novack, MBA, LICSW, ACSW, CSW-G is on the Board of Directors of the Disability Policy Consortium and volunteers with the Boston Center for Independent Living.*

**Related Resources about climate change and heat:**

“[Biden-Harris Administration Unveils National Heat Strategy to Protect Community Health from Extreme Heat](file:///Users/mariannediblasi/Desktop/Desktop%20-%20Marianne%20Dibasi%27s%20Computer/PC%20My%20Documents/Passion/Disability%20Issues/2024-Fall-DI/Biden-Harris%20Administration%20Unveils%20National%20Heat%20Strategy%20to%20Protect%20Community%20Health%20from%20Extreme%20Heat).” *U.S. Department of Health and Human Services*, August 14, 2024.

Blau, Max and Swaby, Aliyya. “[How Georgia’s Small Power Companies Endanger Vulnerable Customers](https://www.propublica.org/article/how-georgia-small-power-companies-endanger-vulnerable-customers).” *ProPublica*, January 25, 2024.

Dhenin, Marianne. “[How Disabled People are Left Behind in Climate Disasters](https://newrepublic.com/article/174497/disabled-people-left-behind).” *The New Republic*, August 31, 2023.

Garza, Frida. “[An Unlikely Line of Defense During Heat Waves: Food Banks](https://grist.org/extreme-heat/an-unlikely-first-line-of-defense-during-heatwaves-food-banks/).” *Grist*, September 6, 2024.

Marienschek, Ida. “[How Readers Stay Cool in a Heatwave – When Air Conditioning isn’t Enough](https://www.theguardian.com/us-news/article/2024/aug/03/how-to-stay-cool-heatwave-extreme-heat-temperatures).” *The Guardian*, August 3, 2024.

**Aging with a Disability**

**By Penelope Ann Shaw**

May 2024, I turned 81 years old. This was definitely a milestone. The number was disruptive and is giving me pause for thought about my past and my future. I am now more aware of the press of time. Seeing myself in a mirror confirms that I'm old, although I do not feel old.

There is a vast literature on aging. Successful aging is often defined as living a high-functioning disability-free life. This is a biomedical definition, rather than one that promotes active productive older years. Personally, I declined functionally 23 years ago from a rare disease. Therefore, I have already developed skills to adapt to my physical limitations.

My condition is stable. I thrive because I'm curious. I like to read and write. I like ideas and being intellectually stimulated across a broad range of subjects. Luckily, my disability does not interfere with having a meaningful life.

Being older, I am now taking a life course perspective of reflecting on my life. I take nostalgic journeys beginning with my early years and ancestry. I was born in Detroit and raised in Michigan surrounded by the Great Lakes. I think about the Thomas Shaw House built in 1843 by my great-great-great grandfather who took his family to the Michigan Territory as part of the Westward Expansion. His house is now in a historic village. I would like to go back to Michigan and visit sites that were important me, but because of the complex logistics of my care I am unable to go in-person. Instead, I have virtual visits.

I remember significant places and experiences. Summers spent at Camp Westminster enjoying nature, swimming and canoeing. St. Mary Academy where I went to boarding school for a couple years. Ypsilanti State Hospital for people with psychiatric diagnoses where I volunteered as a teenager. The campus of University of Michigan/Ann Arbor where I earned academic degrees in French Language and Literature. I especially remember my two undergraduate years of study in France at the universities of Grenoble and Strasbourg.

I remember past professional careers. Teaching French and English to international students at the University of Michigan. Teaching French to Peace Corps volunteers going to French West Africa at the College of the Virgin Islands. Directing a program of English in the Dominican Republic in 1972-73 for homeless people so they could learn enough English to get off the streets by working in the new tourism industry. Teaching English to international students at Boston University's Center for English Language and Orientation Programs. From there, I was recruited to be the first director of the ESL Program at UMass/Boston. I also taught mid-career international government officials in the Mason program at the Kennedy School of Government at Harvard. I found work on international development extremely satisfying.

Today, I identify as both disabled and older. Both groups have rights and protections. Many of the latter grew out of the Emancipatory Gerontology movement. Resources include the U.N. General Assembly Principles for Older persons, the U.S. Older Americans Act, the National Institute on Aging, the National Elder Law Foundation, and the National Bar Association Commission on Law and Aging. Here in MA, we have the Executive Office of Elder Affairs and the Governor's Council on Aging. There are also elder rights, justice and services advocacy groups including AARP and the Gray Panthers. Regrettably, I have aged out of protections provided by the MA Disabled People's Protection Commission because this agency is stronger for people who are living in nursing homes than the Long-Term Care Ombudsman Program.

Those of us in the disability community can contribute to successful aging by sharing our philosophy of living and focusing on our abilities. We can show others that people with differences can live well and being disabled does not inevitably lead to a poor quality of life.

My ability to live well is facilitated by residing in a great town. Everything I need is nearby and accessible – the public library, town hall, banks, pharmacies, restaurants, and farmers market. There are also activities specifically for older adults such as at the local senior center and through the Osher Lifelong Learning Institute at U Mass/Boston which offers lectures, courses and trips through the local public library.

In these ways I have a rich life. However, I am mindful of my future and my journey's conclusion. I ponder longevity. At age 81 how much time remains? What should I do with the last chapter of my life? If I live to be 90, will I have declined even further? Will I still be able to travel around in an electric wheelchair or will I be stuck inside and bored? How do I reach closure? Are there things I'd like to do before I pass on? Reasons I'd like to live longer? I am thinking about these things.

When thinking about being old I sometimes compare myself to friends who are about the same age and do not have disabilities. They have more autonomy, fewer limitations, and can travel more easily. They can come and go in all kinds of weather, while I am unable to take my electric wheelchair out in rain or snow.

I have lived a long and interesting life. I am thankful I majored in the humanities in college because they promote reflection about the human condition. The humanities look for answers to enduring questions. Why are we born? What does it mean to be human? What is our place in the world? What is the meaning of life? Why do things happen the way they do? Why do we die?

In conclusion, I am healthy and independent in important ways.  Many people do not live as long as I have. I am aging well, my disability notwithstanding. Like everyone else, I need to have the courage to face that I live in a physical body and my time is limited. I must accept the inevitability of aging, the end of my life's journey, my own mortality.

As I age, what I am most concerned about is, I live in a nursing home with daily challenges to get the care I need. I fear mental decline and not being able to advocate for myself and therefore, possibly being neglected.

*Penelope Ann Shaw, Ph.D., has a complex physical disability from Guillain-Barre Syndrome. She is a state and national advocate who uses her personal experiences to push for public policies that will improve the lives of children and adults with all types of disabilities. In Spring 2020, she was appointed as a member of the White House Coronavirus Task Force's Coronavirus Commission on Safety and Quality in Nursing Homes.*

**Caring for Each Other**

**By Joan Burrows**

We all need to understand and meet the needs of our aging population, including those who are aging with disabilities. We will all experience some part of it, either ourselves or with relatives and friends.

We often read about the need for people in our lives. It is true and extremely important. It gives people a big lift just to have a visit and chat, to get outside for a ride or a walk, to play a game of checkers, to go to a movie or local concert. "People who need people" is so true and it becomes more important as one ages and, perhaps, can no longer get out on their own. Engaging with people is imperative to ones' health. I am 93 years old and can 100% attest to this.

Every day, I hear about the needs of friends who are in their 60's and 70's, some of whom have friends and family members who are also older. Recently, two friends chose to stop eating and have died. They preferred death over the life they were living, even though were not seriously ill. In my small group of friends, there are two who were so unhappy, they chose death. I can only imagine how many more people there are who are in that situation.

We need people who care! It is not just a job to be a doctor or caregiver and get paid; sometimes for care that is not even given. What does "care" mean? To me, it means a person who asks about you, your life, and your needs; whether it’s a doctor, a clerk, or a friend. I taught music and could only teach each person by getting to know them. I do not think a doctor can do their best if they only look at the medical chart. I can tell right away if the person on the phone or at the bank is a caring person. Unfortunately, I find it rare!

In Acton, we used to have a program called, Friendly Visitor. Twenty-three years ago, I became a visitor after my husband died. I could not continue providing the physical care that some people needed but there were many who just need company – a walk, a meal out, a chat about old memories, someone to play cards or board games with. There were two people I visited regularly, who I loved. I still have their memories in my heart and pictures on my wall. I often wonder who benefited the most, them or me. At age 70, I felt needed again.

I recently mentioned the Friendly Visitor program to the Visiting Nurse agency and received a positive response. I hope to work on getting the Friendly Visitor program reinstated. That would definitely make me feel like I am still useful, but more importantly, it would restart this valuable program. Not only would it benefit some of the oldest members of the community, but it would also benefit all the visitors who offer their care and companionship.

*Joan Burrows studied music in New York City 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 caring companion for people with disabilities and seniors.*

**As if They Didn’t Exist, As if None Died Before Their Time:**

**COVID Fictions and Nursing Home Residents**

By Margaret Morganroth Gullette © 2024

***How should our society remember COVID; how should people write about it?***  It would be a tragedy, a scandal, and a national shame to forget the people residing in nursing facilities who happened to be living there in 2020-2021. COVID hit them particularly hard, in the very places responsible for their safety and well-being, where they were helplessly exposed to contagion and death.  Out of the 1.4 million the government was responsible for in 2019, 132,000 or more died in that first year before the vaccine was invented. They died twenty-six times as often as community dwellers, the other group of US Americans--us.

About community dwellers, a quip went viral, describing us as "the middle class hiding while working-class people bring them things" (Sigrid Nunez, *The Vulnerables,* p. 98).  Residents were not, however, middle class; some had once been, but being there meant they had become indigent. They weren't hiding. Most of them were old, many were living with some disability. In about 13,500 facilities, out of the 15,477 in the country at the time, they were endangered – left unprotected, without proper Personal Protective Equipment (PPE, masks) or adequate staffing. With roommates and aides coming in and out, the disease could enter at any moment. Few had a place to move out to Most died without having loved ones beside them.  During that time, their plight was a media story. Now they seem to be forgotten.

What novelists have to tell us about residents in those institutions in the COVID Era is therefore important. If they say nothing, which seems to be the case, that is in its own way even more important. Oblivion is a social fact too. The marginalized know this better than anyone.

The title of Sigrid Nunez’ 2023 novel, *The Vulnerables*, suggests that she could have been aware of the main targets of the coronavirus at the beginning of the US pandemic, which is when her book--like all other COVID novels I have read--is set. But by page seven, the narrator, apparently in her seventies like Nunez, has been told that *she,* not a nursing home resident but a New York City writer with an apartment, ought to be more careful about contagion. A "young friend" warns her against "wandering about the streets for hours." "You're breaking the rules, and you know it."  "A *vulnerable*, she called me. You're a vulnerable, she said. And you need to act like one."

"Vulnerable" was the year's primary keyword, as 2020 slowly ground down much of the population of the globe. COVID novels typically signal the authors’ knowledge of safety measures: getting out of cities, masks, six feet of distance, sanitizer, two-week quarantines when sick with the virus, and lockdowns to minimize public transmission. US novels are empathetic about social conditions in the community:  schools and playgrounds had closed; people who could stay home were isolated and had too much time to think about risk.

Nursing home residents do come into Nunez's novel once – only in the narrator's distant past, when her Brownie troop was obliged to visit them with Valentines and sing.

Those people – holy moly, what had happened to them. What calamity had bleached and bent and shriveled them?. . . so unlike us – I don't believe these are *Homo sapiens,* the troop smart aleck said.​

The warbly voices, the shakes, the drool, the munching mouths. . . A nauseating mixture, the cheap perfume of the sachets and the stench in the air.. . .

It was almost done. We were almost out of there. Soon we'd be able to breathe freely again. (p. 60)

But as a child she embarrassed a resident whose arthritic arm approached her "like a gigantic pink spider." Later, she is shamed into understanding how mean her reaction to him was, while reading Baudelaire's prose poem "The Old Woman's Despair."

Now there are certain powdery or sickly-sweet scents that can bring it back. The fear. The shame. The old man sadly shuffling back to his seat. My mother's anger. The Baudelaire. (p. 61)

What the author made more memorable are the child’s vivid, ableist, ageist, dementist attitudes (to the residents’ voices, muscle movements that might derive from Parkinson’s; physical ugliness, scents), disavowed as “shame” but brought back even in the present by almost any irrelevant trigger.

From a progressive point of view, the history of literary and visual representation in English can be said to be a story of bringing forward and listening to the voices of forgotten categories of people. *Jane Eyre’s* Madwoman in the Attic, Bertha Mason (1847), was heard by Jean Rhys in *Wide Sargasso Sea* (1966). The enslaved Jim of Twain’s *Adventures of* *Huckleberry Fin (1885)* was transformed into the remarkable first-person narrator, *James,* by Percival Everett (2024).

Wounded male veterans don’t wait so long for representation: The WWII soldier who wore metal prostheses in place of his lost arms and the soldier with PTSD appeared one year after the end of that war in *The* B*est Years of Our Lives* (1946). The veterans of the war on Vietnam, which ended finally in 1975, could see themselves as early as1978, through Jon Voight ‘s sexy paraplegic in Hal Ashby’s *Coming Home.* People with hearing loss can watch Mary Matlin, people with dwarfism can admire Peter Dinklage.

It's surprising to discover how novels representing residents of nursing facilities abounded before COVID; some were best sellers. There are sizable audiences for easy-reading pseudo-memoir, genre fantasies, and comedies of life inside with new pals. In the memoir space, long plots flash back to the earlier, entertaining periods of the life course, filled with events and trouble, circus-as- synecdoche for that time of life. The current, later years are assumed to be static and boring (Sara Gruen’s *Water for Elephants* may be the best known). Some writers fight the allure of youth in light-hearted fantasies about old, bold residents who are mobile enough to escape, clever enough to solve murders, or cutesy in the oddity of their characters. A title like *The Great Escape from Woodlands Nursing Home* (2020)gives the flavor.

Doing both – representing residents diversely and their settings realistically – seems beyond the publishing houses' interests or the desires of most fiction readers. Nonfiction may be the wise recourse but that's another story.

This dearth makes the film *Help* exceptional, as a work of art that goes deep inside, with documentary-level detail and heart. This British TV drama (2021), written by Jack Thorne, tells the story though a Liverpool girl (played by Jodie Comer), who finds herself feeling competent for the first time ever as a paid aide, only to discover that the residents she now cares for deeply, hit by COVID in the first agonizing days, are ignored by the National Health Service responsible for protecting them.  The episode when, to help rescue a heavy, suffocating resident, she must rely on a man with early-onset Alzheimer’s forgetfulness, treats that man as a cooperative responder. The sequences where she realizes that the ambulances are going for community dwellers, not going to arrive for her distressed, coughing, breathless charges, tell that excruciating part of the story. *Help* casts light on government failures of rescue, in the US and in other nations.

Perhaps it is early days yet for imaginative justice – for ​writers to capture the deepest history of the COVID Era, about older adults and those with disabilities inside those institutions – the terror, suffering, and heroism, the scandal of government abandonment, the shame of forgetting those trapped in failing institutions, the voices and fates of those left behind. We are waiting to see.

Margaret Morganroth Gullette is the author of [*American Eldercide: How It Happened, How to Prevent It*](https://press.uchicago.edu/ucp/books/book/chicago/A/bo236968182.html) (October 2024, U of Chicago Press). She is an internationally known author of  prize-winning books, including [*Ending Ageism, or How Not to Shoot Old People*](https://www.rutgersuniversitypress.org/ending-ageism)and is a Resident Scholar, Women's Studies Research Center, Brandeis.

**Additional Resources:**

Gullette, Margaret Morganroth. [*American Eldercide, How It Happened, How to Prevent It*](https://press.uchicago.edu/ucp/books/book/chicago/A/bo236968182.html)*.* University of Chicago Press, October 2024.

Nunez, Sigrid, [*The Vulnerables*](https://www.penguinrandomhouse.com/books/736909/the-vulnerables-by-sigrid-nunez/)*.* Riverhead Books, November 7, 2023.

*Help*. Directed by Marc Munden, 2021. Streams on Netflix.

Waldman, Katy. “What COVID did to Fiction.” *The New Yorker*, June 17, 2024, pp. 62-64.

[*The Big Move*](https://iupress.org/9780253020642/the-big-move/)by Ruth Ray Karpen, Helen Q. Kivnick, and Anne M. Wyatt-Brown, Afterword by Margaret Morganroth Gullette. Annotated bibliography of American fiction about residents goes back before Social Security and Medicaid to John Updike's *Poorhouse Fair* by Margaret Morganroth Gullette. Indiana University Press, March 2016.

[Good Reads](https://www.goodreads.com/list/show/120986.Assisted_Living_Facility_Retirement_and_Nursing_Homes_FICTION), listing of fiction books that feature Assisted Living Facility, Retirement and Nursing Homes as a setting.

**LOVE & INTIMACY CORNER**

**Ella: An Inclusive Fairy Tale**

**(With thanks to Cinderella)**

**By Ms. Love**

***This fairy tale has been reviewed by individuals who share the same disabilities as the characters depicted.***

Once upon a time, Ella was visiting the grave of her mother who had died when Ella was a child. Before she died, her sweet mother told Ella that if she ever needed her all she had to do was whistle and her mother would appear in an other-worldly form.

Ella had never tried to whistle for her mother, partly because she wasn't sure what an other-worldly form was. She placed a bouquet of forget-me-not flowers at her mother's grave and told her how much she missed her. Ella picked up her white cane and headed back home through the deep, dark forest. Ella was blind so she wasn't afraid of the dark.

As soon as she got home her stepsisters began their attack. “How dare you leave when you haven’t washed the breakfast dishes *we’ve* eaten off! What are we paying you for if you haven’t let out the seams on our gowns for the upcoming King's Gala? We aren't paying you anything for this week. Nothing at all.”

“But Sisters,” Ella replied, “I need my wages to pay for dog food for Snickers, the dog that followed me home the other day. Where *is* Snickers? I haven’t seen her today.”

“We shooed her out. We don't want a dog barking at us.”

“Oh no! Snickers could be lost.”

“Who cares? Now get to work on our gowns. The Prince will be at the Gala and looking for a wife. I know he will choose one of us. And don't call us sisters anymore. We may be stepsisters by marriage, but we don't want to acknowledge that we are related to a blind person.” And with that, the stepsisters slammed shut the door to their bedroom.

Ella sat on the floor with one stepsister’s gown on her lap and let out the seams because both women had a fondness for eating pastries, which had added girth to their bodies. Ella sewed in patches of fabric that she took from the hem so the gowns would once again fit her stepsisters. Her mother taught Ella how to sew long ago. She learned to pay attention to the feel of the fabric, how to use self-threading needles, and organize the spools of thread by color in her sewing box. Her mother had told her she could do most things non-disabled people could do, but she would just have to be creative in how she did them.

Ella was a well-thought-of seamstress in the village and could have earned her way in life by sewing but her stepsisters insisted she had enough work making them look beautiful and taking care of the household. They said because she was disabled, they didn't have to pay her the going rate for the work she did, and she wasn’t worth more money. They told her this often.

Ella sighed remembering their words, then she heard someone whispering behind her. “Psst, it’s your friend, Wheelaria. I am sticking my head in the window.”

“This isn't a good time to visit. My stepsisters are in the cottage, and you know how they feel about people with disabilities. Afterall, they were all too willing to start calling you, Wheelaria, the name that the village bully gave you when your parents were in a foreign country earning money to pay for your medical equipment. Soon the whole village felt pressure from ableists and bullies to call you Wheelaria.”

“Yuh, the whole village makes it quite clear how they feel about me needing to use a wheelchair. I have something to give you. You know that since I’m a wheelchair user, the only job in the village that’s open to me is with the Parks and Recreation Department disposing of trash?'

“Yes.”

“Well guess what I found? Someone threw out an invitation to the King's Gala! Can you imagine someone throwing out an invitation to the Gala?”

“Wheelaria, *you* should go.”

“I can't. They won't lower the drawbridge for the Gala so I’m not able to roll in with my wheelchair. They say the drawbridge is only to be used by people bringing supplies into the Castle. It’s very frustrating because they’re all able-bodied. Please, go in my place.”

“Yes, dear friend, I will go in your place and afterwards, I’ll tell you all about it.” Ella reached her arm out the window to accept the Gala invitation from Wheelaria.

The next day, the wicked stepsisters sent Ella to the deep, dark forest to forage mushrooms for their dinner. No sooner did she step out of the cottage than she felt something furry against her leg, so she bent down. Snickers greeted her by licking her face. Ella picked up the dog and hugged her. “Oh, Snickers, I was worried about you! Please come with me to the deep, dark forest.”

Snickers helped her to find enough mushrooms to satiate her stepsisters’ gluttonous appetites. As they began to leave the forest Ella heard a horse whinnying at a distance. Then she heard the horse go galloping by her, just a foot or so away. She thought nothing of it, but the next thing she knew Snickers was frantically barking and Ella was knocked to the ground.

Surprisingly, a human being had fallen on top of her legs. A man's voice said, “My Lady, My Lady!! Are you alright? My horse got spooked and started running through the forest. I got knocked off and fell to the ground. When I stood up, I felt off balance and started limping toward the edge of the forest. In the dark, I tripped on a tree root and crashed into you. I am so sorry!”

“I’m okay. My name is Ella, what is your name, sir?”

“How refreshing, you don't seem to know who I am.”

“Um, no, your voice is new to me.”

“I know it is dark in this forest so if you can’t see me, I will tell you who I am. I am Prince HappyHeart, son of the King, and relative of Count Kindness.

“Are you really a Prince?”

“Yes. What are you doing in the forest?”

“My stepsisters wanted mushrooms for dinner and ordered me to go into the forest to forage them.”

“Well for goodness sakes I will tell my father, the King, about such people living in our village who demand that you must wait on them. Ouch, my leg really hurts.

“I am blind and cannot see your leg. Is it bleeding or do you think you broke it?”

“Well, doesn't that get my knickers in a twist. I have a disability, too!”

“Are you also blind?”

"No, I have vestibular issues, which makes me feel off-balance at times and can cause me to fall.  But today I fell because my horse got spooked and ran away, knocking me off. I didn’t fall off the horse because of vestibular issues.  After I got up, I tripped over the tree root and my vestibular issues probably made it harder for me to catch myself. That’s when I fell and crashed into you.

"When you are ready, I would like to help you get up but I think it would be best if we took a moment to rest first.

Prince HappyHeart closed his eyes and took some relaxing deep breaths then told Ella, “I appreciate your kind suggestion to rest. I’m afraid I might have sprained my ankle. After I get up, could I lean on your walking stick to return to the Palace?"

"Do you mean my white cane?  It's something I use to help scan my surroundings for obstacles and to find markers that indicate where I am."

“Oh, thank you for explaining that to me so I understand. The dog who hasn't left your side seems friendly.”

“I named her Snickers because I laugh with her a lot. Snickers showed up a few days ago right when I needed her because I was missing my mother and feeling sad. Her sweet nature and antics have brightened my spirits.”

“Ella, I’m rested and think I am ready to get up now."  Prince HappyHeart held Ella's hands while she helped him up and he let out a whistle in his effort to stand up.  In a swirl of Fairy Dust, Ella's mother showed up where Snickers had been.

“Mother, did the Prince’s whistle bring you back to me?”

“Yes, child. I am glad Prince HappyHeart whistled so I could appear and comfort you! I know you are strong and independent so it was unlikely you would whistle for me to come to you. I changed my form to Snickers so I could keep an eye on you.”

“Can you stay, Mother?”

“I’m sorry, dear, I was only allowed to come down from Heaven long enough to make sure you and Prince HappyHeart met.”

“Was it you who spooked my horse?” asked Prince HappyHeart.

“Yes, but I didn’t want you to get hurt. I’m sorry you are hurt,” Ella's mother responded. “How about you put one arm around my shoulder and the other arm around Ella's shoulder while Ella leads us out of the forest, and we get help for your leg? This will also give you and Ella time to get to know each other.”

The trio navigated through the forest and arrived at the Palace. When Prince HappyHeart introduced his father, the King, to Ella and told him about Snickers and Ella’s mean stepsisters, the King immediately rolled out new edicts and announcements:

* There will be no more stuffy Galas and other events where only some people are invited. Effective immediately, the Castle drawbridge will be permanently left down so the Castle is welcoming to all who use assistive devices.
* Everyone in the Kingdom (even the King) will attend Kindness and Inclusion training. Forever after, everyone in the Kingdom will practice what they have learned from the training. Those who continue to be cruel and discriminate against others will be banned from the Kingdom.
* Instead of boring Galas, the King proclaimed every day to be People's Day. The Kingdom will host free community picnics on the Castle grounds where all who are hungry for food and friendship are invited to eat, be merry, and bring home leftovers.
* All brick pathways around the village will be torn up so village residents using wheelchairs and other assistive devices will no longer trip on broken or uprooted bricks and hurt themselves. Lady Dignity (formerly known as Wheelaria) will oversee all construction and renovations so that the Palace and village will be completely accessible to all.
* People with disabilities will earn 180% of what someone without a disability earns because people with disabilities need to pay additional expenses for disability-related items that are not covered by insurance.

Then the King announced the engagement of his only child, Prince HappyHeart, to his enchanting soon-to-be daughter-in-law, Ella. The King proclaimed that when they are married, he will retire and, henceforth, the couple will be known as the Honorable King HappyHeart and Beloved Queen Ella. Long may they reign!

Everyone was invited to the nuptials, which took place in the deep, dark forest where Prince HappyHeart and Ella literally fell in love. In lieu of gifts, the villagers were asked to bring hearts full of love.

The royal couple and villagers thrived and lived happily ever after.

***The End***

*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.*

To learn more about a new labor rule that would eliminate subminimum wages for disabled workers, read this article by Caitlin Gilbert, Amanda Morris, and Jacqueline Alemany, “[Why Some U.S. Disabled Workers Are Making Less Than a Dollar an Hour](https://www.washingtonpost.com/wellness/interactive/2024/disability-subminimum-wages-contract-labor/).” Washington Post, August 30, 2024.

**INFORMATION BRIEFS**

**Kim Charlson, Perkins Library Executive Director, Receives Highest Honor in Field of Blindness**

Perkins Library Executive Director Kim Charlson has been selected by the Board of Trustees and leadership for the American Foundation for the Blind (AFB) to receive the prestigious 2024 Migel Medal. Named after M.C. Migel, the first chairperson of AFB, this award honors those who have significantly improved the lives of people who are blind or have low vision.

In their announcement, AFB praised Charlson’s accomplished career at Perkins, her history-setting role as the first female president of the American Council of the Blind, and her influential campaigning for the U.S. signing of the Marrakesh Treaty and the adoption of Unified English Braille. Also highlighted were the many leadership roles Charlson holds across organizations and boards that serve blind and disabled communities, including the Federal Communication Commission’s Disability Advisory Committee and Coalition on Assistive Technology, the Library of Congress’s National Library Service for the Blind, and the World Blind Union.

This honor recognizes Kim as one of the top disability champions of the 21st century among previous honorees including Helen Keller, Americans with Disabilities Act author Senator Tom Harkin, social entrepreneur and engineer Jim Fruchterman, and renowned educators Kathleen Mary Huebner, Ph.D and Philip H. Hatlen, Ed.D. The medal will be officially presented at a ceremony in Minneapolis on September 24th.

This honor comes only a month after Perkins School for the Blind’s President of Educational Programs, Ed Bosso, presented Charlson with the Lifetime Achievement Award at the CVI Conference in Boston. Bosso noted, “what sets Kim apart and defines her as a leader is much more about who she is as a person than as a professional. It’s about her character, her values, and her selfless approach to life.” Congratulations, Kim!

# Read more about Kim and a proclamation from the Watertown City Council in recognition of her work on behalf of the disability community in the article by Charlie : Breitrose, “[Watertown Advocate for People with Disabilities to Received Highest Honor in Field of Blindness](https://www.watertownmanews.com/2024/08/16/watertown-advocate-for-people-with-disabilities-to-receive-highest-honor-in-field-of-blindness/)” *Watertown News*, August 16, 2024.

**Mattel Launches New Barbie Dolls with Disabilities**

In July, [Mattel announced](https://corporate.mattel.com/news/barbie-introduces-the-first-blind-barbie-fashionista-doll-and-black-barbie-fashionista-doll-with-down-syndrome-allowing-even-more-children-to-tell-stories-through-play) the addition of a blind Barbie doll and a Black Barbie doll with Down syndrome, created to allow even more children to find a doll that represents them and inspire all children to tell more stories through play.  Both new dolls are part of Barbie’s “Fashionistas” line that launched in 2009 and has now expanded to more than 175 dolls with a variety of body types and skin colors.

Mattel said Barbie partnered with the American Foundation for the Blind and National Down Syndrome Society to "ensure doll designs accurately reflect the community they are designed to represent". The doll comes with accessories such as a white and red cane with an identifiable marshmallow tip and designed with an eye gaze facing slightly up and out to accurately reflect the sometimes-distinct eye gaze of a blind individual. "Unlike other Fashionista dolls, the blind Barbie doll includes elbow articulations to ensure comfortable cane use," the release said.

Barbie collaborated with the Down Syndrome Society to accurately represent physical characteristics of people with Down syndrome including a shorter frame, longer torso and low muscle tone. The doll also has a braided hair texture, a key feature asked for from the Black Down syndrome community.

**National Disability Employment Awareness Month Event**

The Massachusetts Commission on the Status of Persons with Disabilities is excited to host its Annual National Disability Employment Awareness Month Celebration **on Wednesday, October 23rd, 2024 starting at 11 am the Massachusetts State House in the Great Hall of Flags**.

This event, as part of our National Disability Employment Awareness Month celebration, will bring together a diverse group of participants, including people with disabilities, policymakers, employers, human services providers, and other key stakeholders. This year, we are thrilled to broaden our focus to include both employment and the important issue of voting rights for individuals with disabilities.

In addition to our main event, we will host two significant sessions: a Voting Rights Panel titled "Accessible Democracy: Every Vote Counts" and a Fireside Chat titled "Inclusion in Action: Bridging Gaps in Disability Employment". The Voting Rights Panel will explore the challenges and solutions related to ensuring accessible and equitable voting for individuals with disabilities. The Fireside Chat will feature hiring managers and employees with disabilities discussing their experiences, best practices, and strategies for fostering inclusive workplaces.

By convening these important discussions, we aim to promote greater awareness and drive actionable change in both employment and voting accessibility for the disability community.

**State House Event Series Schedule:**

* **Accessible Democracy: Every Vote Counts Panel Discussion**

11am – 12pm | MA State House, Room 437, 4th Floor & Zoom

* **Championing Inclusion: Honoring Employers, Employees, and Legislative Leaders *(Main Celebratory Event)***

12:30pm – 2pm | MA State House, Great Hall of Flags & Zoom

* **Inclusion in Action: Bridging Gaps in Disability Employment Fireside Chat**
2:30pm – 3:30pm | Room 437, 4th Floor & Zoom

If you have questions, please contact the Commission's Executive Director Imene Bouziane Saidi at imene.bouzianesaidi@mass.gov

**To Register and stay up to dates with event details, click on** [this link!](https://www.mass.gov/news/2024-national-disability-employment-awareness-month-celebration)

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