DisABILITYissues

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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Photo courtesy of https://www.mass.gov/topics/accessible-recreation

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From the Editor…

Dear Readers,

In this issue of Disability Issues, I'm pleased to welcome four first-time contributors: Sage Kampitsis, Isabella Rose, David Cohen, and

Stefanie Krantz. Each one brings a distinctive perspective and voice to our pages, and I hope you enjoy getting to know their work.

In recognition of October being National Disability Employment Awareness Month, Sage examines what can happen when a workplace recognizes disability not as something to overlook, but as an important part of an employee's experience and perspective.

With Halloween approaching, Isabella takes us to Salem in an imaginative exploration of family history, disability, accessibility, and what it might mean to finally feel fully welcomed into a place. She also shares her poem "Spoons," a personal reflection on living with disability.

As students return to school, Stefanie looks at the Disability Law Center's efforts to reduce and eliminate the use of time-out rooms in schools and promote trauma-informed alternatives.

David's *Breathing Room* offers a deeply personal reflection on living with OCD, the challenges of mindfulness and meditation, and his eventual discovery of a way to stop fighting his thoughts and find his way back to the present moment.

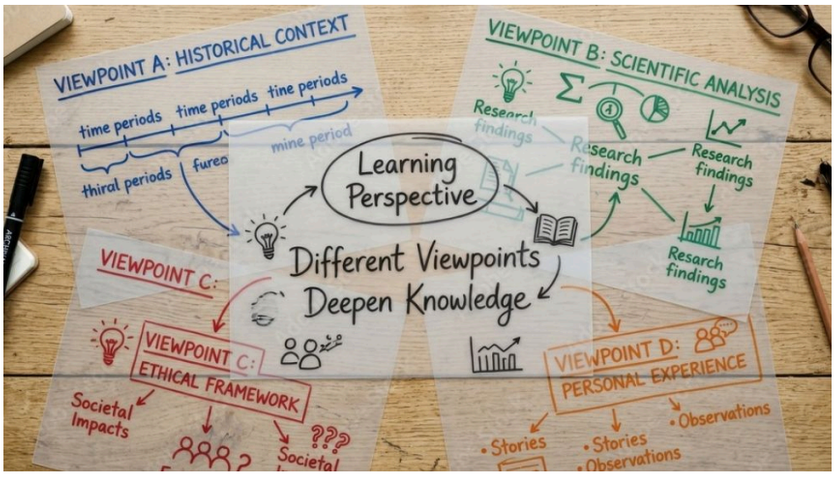
We also welcome back two long-time contributors. Sandy Alissa Novack interviews Wynn Gerhard, who has more than four decades of experience advocating for the rights of people facing guardianship, an issue that can have profound implications for people with disabilities. Penelope Ann Shaw shares how the internet has enriched her life, from research and writing to staying intellectually engaged and connected with others.

We hope this issue inspires you to share your own experiences, ideas, and perspectives. If you have a story you would like to tell, consider becoming a Guest Contributor or joining our editorial board. Please contact me, Marianne DiBlasi, editor, at disabilityissues@disabilityvisibility.com.

Thank you for reading and for being part of the *Disability Issues* community.

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 in the Workplace: A Strengths-Based Approach

by Sage Kampitsis

When I was accepted into a graduate internship program at a hospital in Massachusetts, I believed my Disabled identity would benefit my work, but I was also very wary of social stigma. Narratives around disability often position Disabled people as the ones things happen to, never as the "doers" (Conroy, 2013).

Within this social context, disability appears unfavorable in the workplace – an environment that places a high value on productivity. One outcome of this narrative is the widespread belief that the best way for an employer to validate a Disabled employee's competency is to look past their disability. Therefore, I hoped that my internship program would largely ignore my disability so that I could be seen as a competent worker.

However, rather than ignoring my disability, my internship openly acknowledged it, and over time came to realize that Disabled workers can hope for better than a job that sees us as competent "in spite of" our disabilities. Instead of viewing my Disabled identity as a deficit, the program framed it as an asset to our team, and staff consistently reinforced this framing to me throughout the year I worked there. This difference in approach improved my experience as a Disabled employee and benefited the program as well. In offering an alternative, strengths-based framework for disability in the workplace, and highlighting some ways that my internship put this approach into practice, I hope other employers are able to bring this perspective into their own interactions with Disabled employees.

The reason that, despite concerns of stigma, I was confident my Disabled identity would be an asset to my work, is because I have both read about and experienced the many strengths of the Disabled community. Throughout Disabled people's lives, inequitable social conditions force us to navigate a largely inaccessible world. We have to find innovative solutions to accomplish tasks that able-bodied people take for granted. This experience creates strengths in being flexible, thinking outside the box, tolerating uncertainty, and related skills. Grouped together, this skillset is often called "Disabled creativity" (Jones, 2022).

Though staff at my internship perhaps did not know this specific terminology, they communicated an understanding that disability shapes thinking, and that Disabled employees are an important part of the innovation that is bred from a socially diverse workplace. Throughout my internship, my colleagues continuously collaborated to create a highly accommodating environment beyond what was listed in the ADA paperwork. They wore masks when I joined a room, made meetings hybrid when I needed to travel for medical care, and staff regularly checked in with me about my access needs.

During one of these check-ins, I said to a staff member that I was self-conscious about causing the organization to deviate from its norms. Her response was something I never thought I would hear in the workplace: "An individual perspective on disability is of course going to make you feel like the weight of this is on you, but we are doing this because as an institution, accessibility is something we care about. It is an honor to be doing the work to create an accessible space where experiences and perspectives like yours have a place here. "Rather than accommodating disability because the law requires it, staff demonstrated a genuine understanding of the importance of disability inclusion to create a more enriched workplace environment.

Because the organization was not only accessible but openly welcoming of every part of my Disabled identity, I did not need to concentrate on access or perform to an able-bodied image. Instead, I was able to concentrate more fully on my work. This allowed me more space to lean into my own Disabled creativity as I moved through tasks, and I was able to create more projects and find more solutions to problems than in previous jobs. I took on more responsibility, shared more ideas in meetings, and created more drafts and prototypes during projects.

Throughout these processes, my workplace consistently communicated that my Disabled creativity was seen and understood to be an asset. During debriefs after interactions with patients, on multiple occasions a program staff member told me that she believed my lived experience with disability created an approach to our work that schooling cannot teach. After I gave a presentation rooted in disability justice principles, I heard from numerous colleagues in the following days about its impact and the need for this perspective in the space. Another intern even cited the ways disability informed my thinking as something that had a marked impact on their learning that year, highlighting the program's success at welcoming my Disabled creativity into the space.

At no point during my internship did I need to prove my competence "regardless of" my disability. Instead, I was given space to bring my Disabled creativity into the workplace, and the organization valued what I brought to the table because of it. I thought that my ideal job would be one in which my disability was ignored, but really, my workplace ignoring a major part of my identity was only the best-case scenario when my identity was framed as burdensome.

When society perpetuates the narrative that skillful work and disability cannot go hand in hand, employers may feel it is best to look past employees' disabilities. In doing so, workplaces miss out on the many strengths that accompany disability. Alternatively, when Disabled identity is acknowledged and supported, and the rich skillset born from lived experience with disability are valued, employee satisfaction, productivity, and quality of work can all increase. I am grateful to have had a work experience where I was appreciated not "in spite of" my disability but because of what my experience with disability contributed. I hope more employers take the initiative to create this same sort of environment.

Citations:
Conroy, C. (2013). Paralympic cultures: Disability as paradigm. *Contemporary Theatre Review 23*(4), 519-531. https://doi.org/10.1080/10486801.2013.839171

Jones, D.R. (2022). Reclaiming disabled creativity: How cultural models make legible the creativity of people with disabilities. *Culture & Psychology, 28*(4), 1-15. https://doi.org/10.1177/1354067X211066

Sage Kampitsis is a graduate student in the Master of Social Work program at Westfield State University. Since becoming Disabled in 2022, Sage has had an interest in the Disability Pride movement and deconstructing deficit-centered models of disability. In the internship described above, Sage collaborated with patients and staff to facilitate the inclusion of patient input during hospital policy decisions.

The Gentlest of Giants: An Interview with Attorney Wynn Gerhard

by Sandy Alissa Novack

Sandy Novack (SN): Welcome, Wynn! Can you tell our readers how you got interested in law, social justice, and protecting the vulnerable?

Wynn Gerhard (WG): I was always interested in organizing and advocating for positive change. When I was about 12, I went to the UN to hear Fidel Castro for a school paper. I was elected President of student government in high school, advocating for students' rights and more transparency, with a slogan of "Win with Wynn!" I grew up in the New York City area and helped start a tutoring program for students in Harlem. Every summer during college, I worked on organizing activities for low-income youth in the city and advocated for their interests.

SN: Tell us about your decision to go to law school.

WG: It was partly based on my experience in college, 1967-71, working on civil rights, women's rights, and anti-war issues; and partly

on my two-year national service VISTA experience after college, organizing in a low-income community to establish a free health clinic. I wanted to continue to do public interest, social justice legal work, protecting and expanding rights. I went to the University of Wisconsin-Madison Law School, where I had real life legal clinical programs, including representing inmates in a women's prison. I also worked for years with a public interest law firm, advocating with state government for community groups around improvement in health care, elder rights, environmental and educational laws, much like I do now!

SN: What did you do after law school?

WG: After law school, I worked for a Massachusetts judge overseeing a Consent Decree which required Boston Housing Authority to comply to protect the 50,000 tenants' rights to fair housing, rent calculation, building maintenance, and representation.

From there, I took a job as Director of the Elder Law Unit at Legal Services of Cape Cod and the Islands. There, I worked with amazing elder advocates. Cape United Elders, focused on nursing home resident rights. Together, we enforced the Massachusetts Attorney General's Nursing Home Consumer Protection Regulations. But it was when I worked as the Managing Attorney of the Greater Boston Legal Services Elder Unit that I realized the impact that laws and Court processes at the time governing Court-ordered guardianship could have on the rights of my incapacitated older adult clients. I have now worked in guardianship matters for about 43 years, advocating for stronger due process protections and rights for people facing guardianship.

On one hand, if an elder was incapacitated, at risk, and unbefriended, there was no way to appoint a qualified guardian because Massachusetts did not, and still does not have, a statewide, publicly funded guardianship program, despite years of advocacy.

On the other hand, there was a hospital to guardianship pipeline, where hospitals would petition for guardianship to free up a bed, and the Court would order guardianship with no notice or right to counsel for the person facing guardianship, resulting in swift placement of the elder in a nursing home, loss of former home and possessions. We advocated for years to strengthen due process protections and rights for unbefriended adults facing guardianship.

The Boston Globe's Spotlight team reported on these issues in 2008 in a series that included "Courts Strip Elders of Their Independence." The reporting helped bring attention to the need for reform, and in 2009, the Massachusetts Uniform Probate Code took effect, providing important due process and substantive rights for people facing guardianship. I am very proud to have played a part in this change. Among these protections is the right to an attorney for people facing guardianship.

SN: What is the difference between guardianship and conservatorship, and what does each one involve?

WG: Both guardianship and conservatorship are governed by State law and Court process. My work involves guardianship of adults, as opposed to of children. Court rules require the filing of a Petition for Guardianship or Conservatorship, notice to the person facing

guardianship, right to counsel, medical evidence of incapacity in an 8-page Medical Certificate or Clinical Team report, hearing and right to object on the issues. Only the Court can issue a Decree/Order of Guardianship or Conservatorship. Guardianship is authority over medical and health related decisions. Conservatorship is authority over financial issues and decisions.

There are alternatives to court-ordered guardianship, such as choosing and implementing a trusted Health Care Proxy for medical decisions, or a Durable Power of Attorney for financial decisions.

Guardianship should always be the last resort option.

Adults who may need a guardian can include people with cognitive decline, mental health or substance misuse issues, traumatic brain injury, intellectual or developmental disability, who are unable to care for themselves, or make decisions. The burden is on Petitioners to prove these elements, and the person facing guardianship can object, and introduce independent medical evidence.

SN: Can you give us some examples of situations in which guardianship might be considered, and explain why it may not always be the best or only option?

WG: Person A is an 18-year-old developmentally disabled adult who is graduating from high school and living with her mother. She has received support at school through an Individualized Education Program (IEP) and services under the ADA. She consults with her mother about decisions and is able to articulate her decisions and reasoning. Her school counselor meets with her and her mother and recommends that the mother obtain guardianship for her daughter.

Person B is an 85-year-old woman with COPD and some cognitive decline who lives alone in subsidized housing. She falls in her apartment, goes to the emergency room, and is admitted to the hospital dehydrated and suffering from a urinary tract infection.

Person A and her mother should not be steered into a school-to-guardianship pipeline as their only option. She should have other alternatives, such as a Health Care Proxy, Power of Attorney, and a newer alternative, Supported Decision-Making (SDM). SDM was developed to support people with intellectual and developmental disabilities. A trusted group of supporters—such as family members, friends, and others who respect the person's preferences and are committed to honoring their choices and decisions—can help the person discuss options and make her own decisions.

Person B should first be stabilized in the hospital to relieve her acute symptoms and then evaluated for her cognitive and physical capacity, including her ability to give informed consent and sign a Health Care Proxy. She may or may not need a guardian to be discharged from the hospital and find appropriate placement, which may include a nursing home.

SN: Who can be a guardian?

WG: A court-appointed guardian must be vetted by the Court and must be a competent adult capable of supporting the person they serve as guardian. A guardian can be a family member, friend, or in

some cases an agency, a professional, or public guardian.

An adult can nominate a guardian in their Health Care Proxy, and the law states that the person named in a Health Care Proxy is the first candidate to be considered for appointment as guardian. However, only a Court can vet and approve a guardian and issue an order of guardianship.

Only a Court can approve fees paid to a guardian. We have a two-tier system of guardianship. If you need a guardian and you have financial resources, you will be able to obtain a court-appointed guardian because the Court will order the guardian to be paid from your resources. If you do not have the resources to pay for a guardian, it's unlikely you will have quick access to a guardian or will only have access to a stranger as a guardian who generally will not provide the level of support services required.

SN: What happens if someone, such as Person A or B in your examples, no longer wants their guardian?

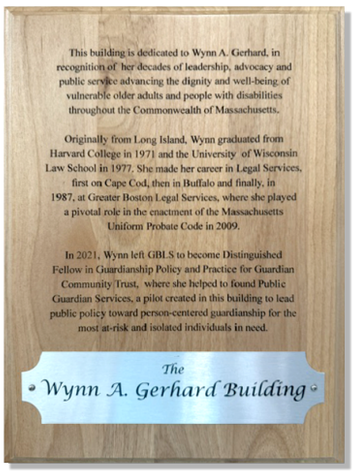
WG: Only a Court can remove or terminate a guardianship, appoint a successor guardian, or determine whether the person still needs a guardian. The person under guardianship, or anyone acting on their behalf, can petition the Court to raise concerns about the guardian.

SN: How should someone choose who to designate as their Health Care Proxy or Durable Power of Attorney?

WG: It is important for a person to pick someone you can trust. Someone who knows your wishes, and values and can make decisions for you, once you become incapacitated.

SN: Your work has been recognized in some pretty special ways. What honors or recognition would you like to share with our readers?

WG: The official green Boston street sign for Wynn Gerhard Road was given to me by Mayor Tom Menino, a unique award that I treasure. The sign was the award; it was not actually attached to a specific street.



Other honors include the Dow-Gardner-Landrum Advocacy Award from Greater Boston Legal Services; admission to the National Long-Term Care Ombudsman Advocacy Hall of Fame; and the Ed Cooper Annual Boston Elder Advocacy Award from Mayor Tom Menino.

I am also honored that the Board of our funder, Guardian Community

Trust, voted to name our Public Guardian Services building in Braintree, Massachusetts, after me, in recognition of my work on guardianship reform.

Guardianship Resources

Public Guardian Services: https://publicguardianservices.org/
A pilot project, providing guardianship and conservatorship services to Massachusetts residents in Suffolk, Norfolk and Plymouth Counties. We serve as a guardian, conservator, or other fiduciary of last resort for those who are decisionally impaired and who have no other suitable person available to assist.

Center for Guardianship Excellence:
https://guardianshipcenter.org/
Conducts research and training on subjects important to guardians and their clients. We offer self-paced learning experiences, live events, and useful job aids to enhance the practice of great guardianship. New content is added monthly.

Office of Adult Guardianship and Conservatorship Oversight, Mass. Probate and Family Court:
https://www.mass.gov/office-of-adult-guardianship-and-conservatorship-oversight-oagco

- Monitors reporting by guardians and conservators of adults
- Collaborates with aging and disability network partners
- Collects data
- Offers an Ombudsperson Service Program
- Provides education about guardianship and conservatorship
    - Alternatives to guardianship and conservatorship
    - Restoration of rights

Massachusetts Guardianship Policy Institute:
https://guardianship.institute
Promotes best practices in adult guardianship and supported decision-making through research, public education, direct service and cross-sector collaboration. A monthly newsletter and a recently released, Report on Public Guardianship – a Ten-Year Review and Recommendations, are available on their website.

Sandy Alissa Novack is the Vice President of the Board of Directors of the Disability Policy Consortium (DPC) and is spearheading DPC's Disability History Project. She is active also with the Boston Center for Independent Living and Dignity Alliance Massachusetts.

Salem, If I Could Choose

by Isabella Rose

Welcome back!
Enter
Exit

If I could choose anywhere in the world to spend one night, I would not choose Paris or the pyramids or a beach with water the color of glass. I would choose Salem, Massachusetts, where part of my family's story began. Specifically, I would choose the Peabody Essex Museum (PEM), though I have never actually set foot inside it. I have been to Salem only three times, and somehow never to this museum, only the photographs and collections I have read about online. This is not a memory; this is what I imagine when asked what it would it be like to spend the night there.

Historical Buildings located on the property of the Peabody Essex Museum - Salem, MA. Photo PEM website.

I already know that I could not spend a night in most of Salem's famous houses. I can manage a few stairs on a good day, but the narrow, winding staircases and uneven floorboards that make those old buildings feel haunted are exactly what my neck and my balance cannot negotiate for long. I would make it partway into the House of the Seven Gables or the Witch House, where Judge Jonathan Corwin once presided over trials that would eventually reach my own family, and have to turn back. So instead, I picture myself dropped off outside 161 Essex Street, where the Peabody Essex Museum's wide street level doors open with the push of a single button, no doorman required, no steps to negotiate.

Visitors in East India Marine Hall. Photo by Kathy Tarantola/PEM.

Founded in 1799 by Salem sea captains who wanted somewhere to keep the strange and beautiful things they carried home across the ocean, the PEM is one of the oldest continuously operating museums in the country. I wonder what it was like back then, when it was still a private cabinet of curiosities for the East India Marine Society, ship captains passing around carved masks and porcelain from ports most of their neighbors would never see. It has grown since into three floors and twenty-five galleries, nearly 130,000 square feet of maritime art, Asian export treasures, and centuries of New England history, all of it, according to the museum's own accessibility page, wheelchair accessible in every public area. The historic houses on the property are the one exception.

I would arrive after closing, when the guards have gone quiet and the last echo of footsteps has faded from the atrium. With cervical spine instability comes dizziness, the kind that makes a staircase feel like a dare rather than a path. I would take the elevator up from the ground floor the way any visitor can, one hand on my cane and one hand free for the rail, no flight of stairs asking my neck and my balance to negotiate with each other.

The fun part is what I would let myself do once the building was mine. I would keep half an eye out the whole night, hoping for an actual ghost, even though I know the real hauntings at the PEM are seasonal, costumed storytellers who perform in the historic houses next door each October. If I timed it right, I might catch them through the window, lanterns bobbing across the dark lawn while I sit safe and level on the inside. I would race, gently, down the empty maritime gallery, past ship figureheads that have stared at nothing for two hundred years, and dare them to blink first. I would find the gallery holding the 1692 collection last, on purpose, the way you save dessert.

That is where my family's story lives. My ancestor, Major Robert Pike of Salisbury, wrote a letter that August, questioning the spectral evidence used to condemn his neighbors, testimony about things no one else could see or prove. That letter has been preserved and digitized through this museum's library, and I would sit with it a long time. Both his fight and mine come down to the same demand. Both ask a person to prove something no one else can witness, and both leave you defending your own reality to people who have already decided not to believe you.

Robert Pike

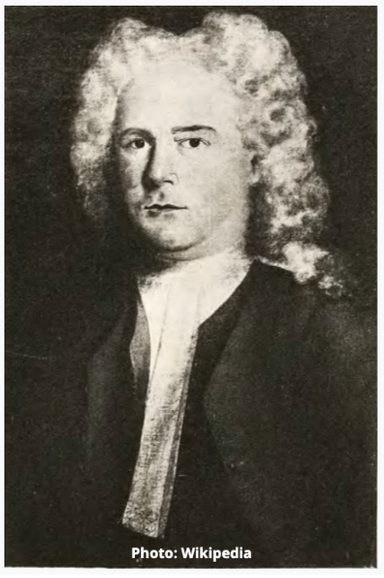


Photo: Wikipedia

Robert Pike stood up for neighbors condemned on evidence nobody could see. I have spent years trying to be believed about a body that misbehaves in ways no one else can see either.

I would not pretend my body could do more than it can, even in a fantasy. I would keep my cane close and move slowly, watching for the dizziness that cervical spine instability brings on without warning, and by midnight I would need to stop moving altogether. I would find a bench, because the museum has them scattered through every gallery, and settle in with my Bucky cervical pillow behind my neck and a cushion at my lower back, honoring the instability and pain that never actually clocks out, not even for an imaginary adventure.

Somewhere past midnight, I would stop being a guest and start being a granddaughter of Salisbury, sitting with a letter my ancestor wrote before he knew his descendants would need the same kind of defending. I would talk to him a little. I would tell him the fight for belief did not end in 1692.

By morning, when the light hits the atrium's glass ceiling, I would still be tired in the way my body always is. But I would also be full, the way a night spent somewhere that let me all the way in can leave a person feeling. Not because the ghosts were friendlier here, but because for once the building itself did not ask me to prove I belonged before it let me through the door.

I do not know what it will feel like to visit. But when I finally go, I will not be stopped at a staircase built three centuries ago, in a world that had not yet imagined a chair with wheels, a rollator, a cane, or anyone who might need them. The PEM will be fully accessible to me.

Isabella Rose is a published author, Intentional Creativity artist, and advocate whose writing explores resilience, grief, healing, and the stories that connect us. She is the author of the newly released anthology ***On the Other Side of Grief: A Healing Companion for Your Journey from Loss to Hope****. Living with physical disabilities following a near-fatal car accident, she is a lifelong lover of books, history, and storytelling who enjoys exploring her family's ancestry and spoiling her beloved senior cat.*

Breathing Room

By David Cohen

The present moment. That is what I was searching for my whole life; even if I had never known it. Something was always in the way: thinking ahead to the next thing to do, and the thing after that; continuing conversations I just had, but in my head; feeling not 'just right' in my body; the constant noise of 'what ifs'; the mental struggle against offensive, triggering, intrusive thoughts.

That is a lot going on to find a moment of peace. No comfortable space or relaxation, no calm or insight; just the fight, seemingly for those things. All of this kept me unwillingly distracted from the only place where I could discover my true self; in the present moment. But my present moment had been, for as long as I could remember, intolerable and stressful. While I was physically there, in my mind I was lost, ruminating about the past, worrying about the future, or struggling to mentally outrun my own thoughts. I was mostly never really 'there'.

I did try very hard, though, to separate myself from the noise, to make moments of peace. In a quiet space at home, I would sit as still as I could, adopting a cliche meditation posture, with legs crossed, hands resting palms up on my knees in sideways 'okay' signs. With my eyes barely open, unfocussed toward the floor before me, I tried to clear my mind of the unwanted thoughts and 'static' that interrupted my concentration. I mentally tried to push them away. *No, that's not right. What did the book say?* I had read a book about meditation written by a Zen master. *Let the thoughts pass by like clouds and return my attention to my breath. That's right. Breathing in...breathing out*.

The clouds seemed unending. As one passed, it's as though it had rained and left me soaking, just as another cloud darkened the sky. *Breathing in...* More clouds gathered. *Am I holding my breath?* Distracted, I lost track. *What about my posture? Am I lifting through the crown of my head enough? My back is starting to hurt. Remember to breathe! Right, breathing again, in long and slow, out long and slow...in again...out again. Ahh! My eyes are closed. Am I falling asleep?* I refocused on staying conscious but relaxed, returning my attention to my breath, which then paused at the end of my exhalation. *It feels good resting there; will it start again? Why isn't it starting again? Breathe, breathe!* I took panicked deep breaths, in, out, in, out, and felt a little dizzy. *Slow it down now. Okay, better.*

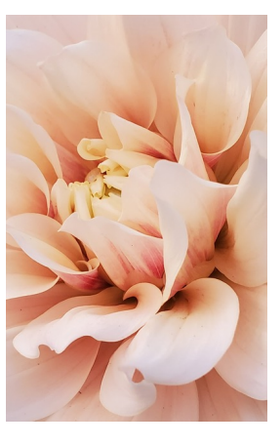
I became very aware of my breathing. I was supposed to stay aware of it for meditating, but awareness became fixation, and total conscious control felt like the only way I would keep breathing. I started to feel confined and unsettled. My breaths became short and shallow in my chest. Feeling overwhelmed, my posture sank, my legs unfolded, and I laid on my side wondering how I would survive while constantly needing to maintain my breathing.

Early forays into meditation, or mindfulness, were fraught with great challenges to say the least. It took many attempts, over weeks, possibly months, before I started to gain a little focus, though my brain still felt like a shivering Chihuahua. Eventually, some form of calm had developed, and I felt a little more relaxed at times. While not technically successful at first, these attempts were actually incredible feats for a brain submerged in the floodwaters of OCD; I can see that in retrospect, but not so much at the time. I had opened a small space inside myself, a little bit of breathing room, that perhaps provided hope for the future. I came closer to the present moment, but it had still eluded my attempts to find it, and to just...sit there for a while, and just be.

One night, twisting and turning in bed, desperately wanting to sleep, but fighting off the intrusions in my head with every ounce of energy I could muster, and my body tensed like an iron ball, it all suddenly crashed down. Every fiber of my mental and physical being exhausted, I stopped dead, my wires cut. All the intrusions, the stress, the worries, doubts, and fears suddenly stopped as well. When I stopped fighting them, they all stopped. I laid in silent surprise as this epiphany sank in. My breathing was happening naturally without even trying. I was there, and that's all there was besides the quiet. When I stopped trying, I made it. I arrived. The present moment and I met for possibly the first time, and it was amazing! It may have lasted mere moments before I passed out into an effortless sleep, trying desperately to hold on to that feeling; only to wake up the next morning drowning again.

While my epiphany taught me a valuable lesson, OCD still outweighed it in my brain 99 to 1. But the experience created a core memory to draw upon later. A subconscious understanding that the more attention we give the 'uncomfortable' thoughts and feelings, the more we teach our brains that they are important and need our attention, so they come up again, thus creating an unending cycle of pain.

It would be many years and many therapists later before I could draw upon that understanding and break the cycle. I found my way back to the present, but this time it would become a welcome place where I would make my home. After decades lost to being anywhere but here, there is no place else I would want to be. Here and now is a magical and wondrous place where everything happens; self-discovery, truth, love, and hope are right here, always ready within. I embrace, with gratitude, this wonderful present moment, where my smile is natural and effortless, ready to stay as long as I can.



David Cohen is a writer in the Pacific NW with lived experience of OCD and other chronic issues. To him, writing is purpose and passion, a process of self-discovery and transformative expression. He writes poetry, short stories, essays, and more, including fiction and nonfiction.

Photo by David; closeup of a dahlia in his garden.

Spoons

by Isabella Rose

She wakes before dawn, not because she is rested, but because pain has beaten the alarm clock again.

Before her feet touch the floor, she takes inventory.
Neck. Back. Ribs. Hips. Breath.

Ten spoons.

The shower costs four. Washing her hair costs one more.
Getting dressed takes two.

By breakfast, she is down to three.

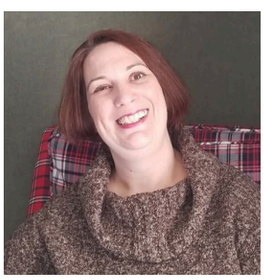
Friends ask what she plans to do today.

She smiles and says, “Take it easy.”

They do not know she has already climbed a mountain.

By noon, the spoons are gone.

Tomorrow, she will wake and begin again.



Isabella Rose is a published author, Intentional Creativity artist, and advocate whose writing explores resilience, grief, healing, and the stories that connect us. Living with physical disabilities following a near-fatal car accident, she is a lifelong lover of books, history, and storytelling who enjoys exploring her family’s ancestry and spoiling her beloved senior cat.

Disability Law Center Advocacy

Reducing and Eliminating Time-out Rooms in Schools

By Stefanie Krantz

In Massachusetts, school time-out rooms with peaceful sounding names are prevalent. Despite labels such as The Zen Den or The Calming Room, many children are traumatized at school when they are involuntarily placed in these rooms, often the size of a closet. The Disability Law Center (DLC) began working intensively on this issue in 2019 after receiving reports of concerning spaces, troubling practices, and significant harms experienced by children placed in these rooms. Parents, advocates, and school personnel reported children experiencing intense trauma related behaviors including school phobias, incontinence, fear of small spaces, emotional shutdown, insomnia, physical injury, regression, and other stress-related behaviors.

Combatting Improper Seclusion in Schools

Photo: U.S. Department of Justice Website

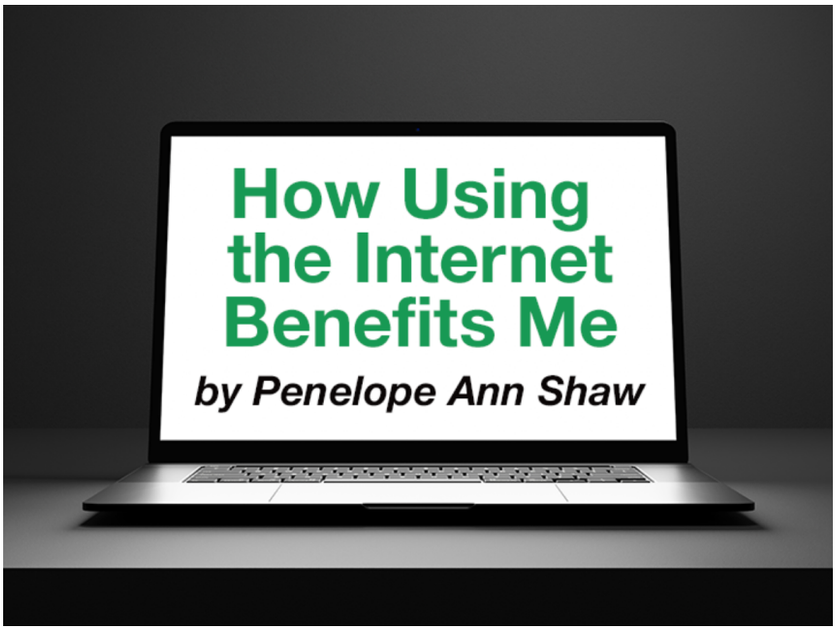
DLC is the Protection and Advocacy system in Massachusetts, with federally derived authority to monitor and investigate places where people with disabilities live and receive services. This includes public, collaborative, and private special education approved schools. In response to the complaints DLC received, we conducted onsite monitoring of time-out rooms across the state and found a wide variance in room usage. Some schools use time-out rooms – even with pre-school aged children – and some schools do not use them at all. This variation was seen across all types of schools; disabilities served, and ages of the children. In schools that regularly use time-out rooms, DLC identified many concerning practices, including placement of certain students in time-out rooms daily, loss of educational services, and isolation from peer groups. We learned that school personnel also experience trauma and sometimes injury from putting children in time-out rooms.

With the information obtained during our monitoring, DLC connected with other organizations and the Massachusetts Department of Elementary and Secondary Education (DESE) to dig deeper into the issue. Together, we developed an advocacy strategy designed to directly change the practices and culture in schools. As part of this advocacy, we met with school personnel, lawyers, parents, and advocates to determine the barriers to change. We also learned that school personnel need to gain a better understanding of alternative options to work with students who are dysregulated.

Fortunately, measures to protect students from harmful time-out practices are progressing. In 2021, DESE issued guidance, *Reducing and Eliminating the Use of Time-Out Rooms During the 2021-2022 School Year.* This guidance provided practical advice for schools on best practices to shift away from the use of time-out rooms. Through our joint advocacy, we identified the need for training on alternatives before the use of time-out rooms can be eliminated. Again, and again school personnel asked, "What will we do instead?" In response to this need for training, DESE released two rounds of grants to provide schools with funding to promote the reduction and elimination of time-out rooms. In addition, DLC, along with our co-sponsors, coordinated and presented two webinars for school personnel to learn about the issue and hear about trauma-informed alternative practices. The first webinar was entitled *Keeping Kids in Classrooms- Stop the use of Exclusionary Time-out Rooms in School* and the second was *Helping Schools Help Students*. Both webinars provided an overview of the issue and offered detailed information on trauma-informed alternative practices.

Meanwhile, DLC continued to strongly advocate for substantial changes in the time-out regulations to expand upon the 2021 DESE guidance and protections for students. DLC also participated in DESE stakeholder meetings to discuss proposed changes in the time-out room regulations. This opportunity allowed for the sharing of ideas and educating people on all sides of the issue. At the conclusion of the stakeholder meetings, DESE issued proposed regulations to the Department of Education Board where DLC provided public comment. The new DESE regulations were approved, and they go into effect in August of 2026. While the new regulations do not fully eliminate the use of time-out rooms as we had proposed, they provide many additional protections for students and promote change in schools across Massachusetts. DLC continues to work across the Commonwealth to help schools change policies and prepare for implementation of the new regulations, identify alternative practices, and move towards best practices. We strongly believe that the resulting changes in policy, practice, and regulations will reduce trauma for students as well as school personnel. We look forward to continuing this work in the upcoming year.

Stefanie Krantz is a senior attorney at the Disability Law Center of Massachusetts. She specializes in education issues and advocates to eliminate restraint and seclusion in our schools. She believes that trauma-informed alternatives work and has dedicated her career to promoting best practices to support the wellbeing of students and educators.



As a person with a disability the internet improves my life every day in multiple ways.

Because of my disability, I use a computer differently. When I am in my chair, it will not fit under a table or shelf, so I sit to the left of the screen. I use my right hand and arm to pick up a light-weight keypad which I put on my lap and proceed.

Using the internet is best way for me to communicate because, due to my disability, my shoulders don't work. Therefore, it is almost impossible to make phone calls. To make a phone call I need to find a place to tilt my wheelchair so that I'm prone, like being in bed, then I use my right elbow to hold the phone up with my elbow. But even then, the other person on the call often tells me they can't understand what I'm saying.

When I am in bed, I have an overbed table with my folders containing notes about topics I might want to write about. I also have access to a dresser bookcase with shelves above and drawers below, providing writing supplies like paper and pens. There is also a shorter bookcase with a shelf for books that I use for writing ideas. My bed has become a quiet private workspace without distractions where reading, drafting, and editing pieces for possible publication is satisfying. When I need a break, I often look at a piece of artwork that I created years ago, which hangs on the wall across from my bed.

Years ago, I wrote a doctoral dissertation for my PhD degree, which took me three years and was a torturous process. I never imagined that the day would come when I enjoyed writing.

I now write and use the internet in the following ways for information and communication.

Through online research, I learned more about Guillain-Barré syndrome, the rare disease that disabled me, and found ways to cope with it better.

When necessary, I use the internet to file grievances about problems in my nursing home facility. Questions are sent to the MA Department of Public Health Bureau of Health Care Safety and Quality, the MA State LCT Ombudsman and/or the Federal Division of Nursing Homes at CMS. I also have the option to contact a lawyer at the Disability Law

Center here in MA for advice and possible representation.

I let our kitchen manager know if I don't get the right food on my meal trays. I need my breakfast cereal, Cream of Wheat, to be thick so it stays on my spoon and is edible. Previous kitchen managers always made sure it was the right consistency. But, one day it was like soup, so I contacted a lawyer at the Disability Law Center for advice on how to get the breakfast I'd been getting for years.

Living in a nursing home, I have researched residents' rights including the room temperature required inside a facility and the MA Noise Law which forbids residents from having the sound of their TV on so loud that it interferes with the sleep of others. This information improved the quality of life for me and the other residents.

One of the most personally valuable ways I use the internet is to check the weather every morning to see what the weather will be. If it rains, I cannot go out in my electric wheelchair. Getting away from

facility provides me with a brief escape from institutional life.

I have researched both federal and state nursing home residents' rights, including the Americans with Disabilities Act, so I can let the management of my facility know what our rights are. Thus, improving the lives of all the residents.

I keep updated on the latest disability news by reading messages sent to me online by disability organizations. I can then reach out to these sources for advice if needed.

Living in Massachusetts I sometimes use the internet to reminisce about my past. For example, I googled the summer camp in Michigan that I went to as a child. The internet is also a way to see online places that I cannot visit in person because of my disability.

I use the internet to stay in touch with friends locally and sometimes to confirm with a friend that we are having lunch at a restaurant.

I use a computer to write and edit pieces to send to editors of various publications. Thinking about and writing these pieces is an interesting way to spend my time. When my pieces are published, I use the internet to share my work with others.

When my wheelchair needs repairs. I send a message to my wheelchair company asking them to come to my facility to do the repair.

In these ways, I stay busy and am never bored while in bed. On rainy days, especially when I spend the whole day there, the internet gives me access to intellectual stimulation and allows me to be productive.

Although my body does not work typically, my mind remains active and engaged. The internet has opened up endless opportunities for learning, writing, creating, and connecting with others. These intellectual benefits are a gift, allowing me to remain productive and engaged even when my physical abilities are limited.

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.

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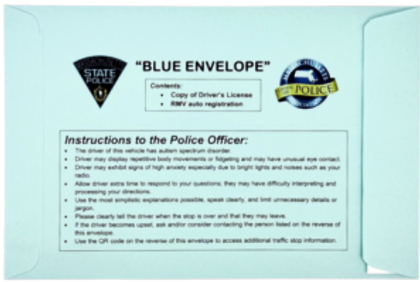

Massachusetts
Blue Envelope Program
Becomes Law

Massachusetts has established a statewide Blue Envelope Program to help improve communication between law enforcement and people with autism during traffic stops and other interactions. Governor Maura Healey signed **An Act Facilitating Better Interactions Between Police Officers and Persons with Autism Spectrum Disorder** into law on June 25, 2026. The law took effect September 1, 2026.

The Blue Envelope is a distinctive blue envelope designed to hold a driver's license, vehicle registration, contact information, and other important documents. Information printed on the envelope alerts law enforcement that a person with autism may communicate, process information, or respond differently during a stressful interaction. The envelope also provides guidance to officers on ways to facilitate effective communication.

The program is **voluntary and free**. Any Massachusetts resident with autism may request a Blue Envelope, and parents or guardians may request one for a minor or person in their care. No medical records, diagnosis documentation, or other verification is required. Residents may request additional envelopes for different vehicles.

The law directs the Massachusetts State Police, in consultation with the Registry of Motor Vehicles, Massachusetts Chiefs of Police Association, and autism advocacy organizations, to design the envelopes. The RMV is responsible for making them available upon request.

The statewide program builds on a Blue Envelope initiative launched by the Massachusetts State Police in 2024. As of September 1, envelopes are available through RMV Service Centers, participating AAA locations, and an online mail-request form.

Learn more about the Blue Envelope Program

Massachusetts Commission on the Status of Persons with Disabilities

National Disability Employment Awareness Month Celebration

The Celebration will take place on Wednesday, October 7, 2026 in the Great Hall of Flags at the Massachusetts State House and on Zoom. ASL and CART services will be provided.

Join individuals with disabilities, family members and caregivers, employers, policymakers, educators, service providers, advocates, researchers, students, and community partners from across Massachusetts for a day of connection, employer and legislative recognition, and an afternoon panel.

11AM – 1PM | NDEAM Celebration.
Great Hall of Flags, Massachusetts State House & Zoom

This year's 2026 Employment Support Champion Honoree is Micah Fleisig, Senior Manager in Disability Services at JVS Boston. Micah has spent more than 25 years supporting people with disabilities in a variety of settings and has been with JVS for the past 15 years.

2PM – 3:30PM | Artificial Intelligence, Disability, and the Future of Work Panel
Room 428, Massachusetts State House & Zoom

Link to registration below:

Registration link

If you have questions, please reach out to Imene Bouziane Saidi at **imene.bouzianesaidi@mass.gov**

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