



Life Matters Journal

V. 8, ISSUE 2 — OCTOBER 2020

THIS ISSUE'S THEME:

Disability Rights



LETTER FROM THE EDITOR

Dear Readers,

This issue of *Life Matter Journal*, on disabilities, has been the most personally meaningful to me in my time as editor. I have cerebral palsy and visual impairment as well as a complex health history. From the trials of being one of few disabled students in mainstream classes in my elementary school, to having to defend my existence to proponents of disability-selective abortion, to a recent experience when assumptions about my disability delayed the treatment of a medical complication, I have experienced many negative effects of our society's failure to fully respect the dignity of disabled people.



I wrote several pieces for this issue. However, I am far from the only person sharing personal experience or expertise here. I am proud to say that all of this issue's contributors have disabilities. We made this choice deliberately, because people with disabilities are often not given a voice even about topics that affect them directly, such as euthanasia or accessibility. Luckily, Rehumanize International has many talented, thoughtful disabled people among its staff and supporters, so many that we couldn't feature them all.

In this issue, Beth Fox and Sophie Trist discuss the unique challenges facing disabled people during the ongoing COVID-19 pandemic. Taylor Hyatt outlines how recent Canadian legislation on physician-assisted-suicide threatens disabled people. And author Kristen Witucki shares her experiences as a disabled parent. I hope these and other pieces help you recognize that our society, while it has made a great deal of progress in the last several decades, still has a great deal to do to respect and protect the dignity, worth, and needs of people with disabilities.

Making this issue even more poignant is the fact that it marks my last as Executive Editor. Rehumanize International is shifting its publication model to focus on the blog and white papers; a selection of the best blog pieces will be published in hard copy on the same schedule as *LMJ* was published. I have really enjoyed my time in this role, and will be continuing as an editor and writer for the blog. The format may be changing, but Rehumanize International is still committed to spreading the message of respect for life through the written word.

For justice, peace, and life,

Kelly Matula

This journal is dedicated to the aborted, the bombed, the executed, the euthanized, the abused, the raped, and all other victims of violence, whether that violence is legal or illegal.

We have been told by our society and our culture wars that those of us who oppose these acts of violence must be divided. We have been told to take a lukewarm, halfway attitude toward the victims of violence. We have been told to embrace some with love while endorsing the killing of others.

We reject that conventional attitude, whether it's called Left or Right, and instead embrace a consistent ethic of life toward all victims of violence. We are *Life Matters Journal*, and we are here because politics kills.

Disclaimer

The views presented in this journal do not necessarily represent the views of all members, contributors, or donors. We exist to present a forum for discussion within the Consistent Life Ethic, to promote discourse and present an opportunity for peer-review and dialogue.

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Life Matters Journal

OCTOBER 2020

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COVID-19 and Disabilities

By Beth Fox, MPH

Editor's Note: While the numbers provided for case-fatality rate and similar statistics were up to date when this article was written, changes in testing capacity and people's activity mean they have changed quickly. See the CDC sites listed in the end-notes for up-to-date figures.

CCOVID-19, the disease caused by the novel coronavirus SARS-CoV2, has been frequently compared to the flu. However, this comparison had the opposite effect of what it should have. The emergence of a novel flu-like illness should be alarming. Saying something is as bad as the flu should be a cause for concern, not relief. I don't say this to cause panic. Panic is not a beneficial response to any crisis. However, let's take a look at what the flu really looks like. Typically, this term is used to refer to the seasonal flu; however, even that is a variable condition. Specific characteristics of the circulating viruses, the length and timing of the active flu season, population immunity from past exposure or vaccination, and efficacy of that year's flu vaccine are all critical factors that influence the severity of the burden that flu causes in the United States.¹ Last season, the case-fatality rate for seasonal flu was 0.096% with 35,520,883 cases; however, the 2017-18 flu season had a case-fatality rate of 0.136% with 44,802,629 cases.² That's an additional 27,000 lives lost to the flu in the 2017-18 season.

Since I studied epidemiology and specifically researched the flu as part of my Master's of Public Health, I was eager to look into the comparisons of COVID-19 and the flu. First, both viruses have similar symptoms, including cough, fever, and fatigue. Both viruses spread primarily through droplets and fomites, active viral particles that remain on surfaces. However, the infectiousness, reported as the basic reproductive value or R_0 , varies. The highest reported R_0 for seasonal flu was 1.53 in the 2017-18 season.³ The R_0 for COVID-19 is still being determined but has been estimated to be between 2.2⁴ and 5.7.⁵ The case-fatality rate in the United States is currently 5.6%.⁶ While the global case-fatality rate is expected to be closer to one percent, this is still over ten times higher than the seasonal flu.⁷ Additionally, while both viruses can lead to pneumonia, the way they do so is drastically different. Influenza viruses primarily replicate in the upper airways, and life-threatening complications, such as pneumonia and acute respiratory distress syndrome

(ARDS), are most often caused by secondary bacterial infections.⁸ However, SARS-CoV-2 binds to receptors which are found abundantly in the lungs, allowing for the preferential infection of lung tissue and resulting in severe viral pneumonia and rapid onset ARDS.⁹ Finally, both the flu and COVID-19 disproportionately affect the elderly and those with underlying health issues.

As a result, COVID-19 has had a widespread impact on the disability community, as this population is three times more likely to have at least one underlying health condition that increases their risk of severe or life-threatening illness from COVID-19.¹⁰ Perhaps, one of the most frightening things that this pandemic has brought to light is the ableism built into much of our healthcare system, despite federal laws prohibiting it.¹¹ Several states had previously published crisis standards of care that would withhold overdemanding medical resources, such as ICU beds and ventilators, from those over a certain age or with specified physical or intellectual disabilities. Only Alabama,¹² Pennsylvania,¹³ and Illinois have appropriately revised their discriminatory guidelines.¹⁴ California^{15,16} and Massachusetts¹⁷ have made revisions but several discriminatory guidelines remain.¹⁸ Georgia issued a reminder to healthcare providers of the federal non-discrimination requirements but didn't address the concerns or recommendations raised by disability advocates.¹⁹ Wisconsin agreed to address discrimination concerns and consult a disability expert as they finalize their guidelines.²⁰ Federal complaints are still pending against Kansas, New York, Oklahoma, Tennessee, Utah, and Washington.²¹ Letters of concern have been sent to the governors of Arkansas, Colorado, Connecticut, Delaware, Florida, Kentucky, Louisiana, Massachusetts, Mississippi, Montana, Nebraska, New Hampshire, New Jersey, New York, North Carolina, Ohio, Oklahoma, Oregon, Rhode Island, Texas, Utah, and Washington D. C.; however, none of these states have responded. Concern over access to care is not limited to the US. In the United Kingdom, where such anti-discrimination legislation doesn't exist, disability advocates are seeking legal recourse after the government refused to release guidelines prohibiting disability discrimination in medical rationing.²²

Finally, let's discuss the moral obligation to follow strict social distancing measures in order to primarily protect the elderly and

disabled. This group is not a small minority. As of 2019, 24.6% of Americans, over 80.75 million people, were disabled or over 65-years old.²³ That's at least one in four Americans who are at increased risk of severe and possibly life-threatening illness from COVID-19. This group is probably actually substantially larger as co-morbidities like diabetes, hypertension, and heart disease, which are not necessarily disabling, have also been found to significantly raise the risk of severe illness. For some perspective, this is just under the combined populations of California, Florida, and New York, which are three of the top five most populated states. Some argue that only these individuals need to stay home. This was the model that Sweden tested. They initially did not issue shelter-in-place orders or close businesses, assuming that young, healthy individuals would contract the virus and build herd immunity, while those at higher risk stayed safely at home. If their hypothesis were true then Sweden should have a higher recovery rate and lower case-fatality rate than the United States. However, the opposite is actually true. The current case-fatality rate for Sweden is 12.06%, higher than both the U.S. at 5.65% and the global average at 6.94%.²⁴ A similar pattern is seen for the percent of critical cases. However, Sweden's recovery rate, 31.44%, is lower than that of the U.S., 68.53%, and the global average of 80.47%. These do not equal 100 percent as case-fatality is out of total cases while recovery is only out of closed cases. Given these data it appears Sweden's hypothesis is not turning out well.

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Euthanasia in Canada: State-Assisted Death Before Life

By Taylor Hyatt

With good reason, Canada prides itself on being a defender of human rights. The Canadian Charter of Rights and Freedoms became law in 1982.¹ Section 7 of the Charter states that everyone has “the right to life, liberty and security of the person.” Section 15 of the Charter lists various attributes for which Canadians cannot be discriminated against under the law, including race, age, and mental or physical disability.²

In the 2015 *Carter* case, the Supreme Court of Canada found that the Canadian Criminal Code’s prohibition on assisting suicide violated the Charter rights of people with disabilities. Some people would not be able to end their lives without help as their conditions changed. In order to do so independently, someone seeking death would need to act sooner than they might wish and miss out on a few additional months of life. This loss of time violated the Charter right to life and interfered with their autonomy. Unlike American legislators³, Canada’s Parliament was compelled to draft legislation covering both assisted suicide and euthanasia⁴.

Thanks to this legislation, Canadian citizens are now divided into two classes: disabled people whose “reasonable” desire to die should be enabled⁵, and nondisabled people whose deaths should be prevented no matter what difficult circumstances they face. Making death acceptable only in cases of disability is clearly discriminatory. These procedures are unnecessary, as well; any disabled person can end their life unaided by refusing food and drink.

The legislation resulting from these efforts, C-14, came into effect in the summer of 2016. In order to qualify for life-ending measures, a person must be at least 18 and eligible for government-funded healthcare, and have a “grievous and irremediable” medical condition. This means “a serious and incurable illness, disease or disability...in an advanced state of irreversible decline” causing “enduring physical or psychological suffering that is intolerable...and that cannot be relieved under conditions that they consider acceptable.” Their request for death must be made voluntarily. Originally, the person’s death must have been “reasonably foreseeable,” and they had to give informed consent at the time of the procedure.⁶ These requirements were changed in a later version I will also examine.⁷ Informed consent included being made aware of other options, such as palliative care⁸. It is important to note, though, that knowing about other options is not the same as being able to *access* them.

According to the initial *Carter* decision, the law should include “stringent limits” that are “scrupulously monitored and enforced.”⁹ In addition to holding the “opinion” that the interested person meets the eligibility criteria, the doctor or nurse must¹⁰ ensure the request was written, signed and dated by the both the person in question and by two witnesses who are also at least 18 and who do not provide care to the person who wants to die; own or operate a facility where they live or are treated; believe that they will benefit from the person’s death (including financially) or; be connected in some way that could prevent objectivity (i.e. friends, relatives). The law also required written confirmation of the medical professional’s diagnosis from a second, independent medical practitioner, who, like the witnesses, must be unconnected to the person requesting euthanasia. Furthermore, 10 days had to pass between the request and death, unless death or loss of capacity were imminent, and the person must be provided both (1) an opportunity to withdraw their request and (2) reliable means by which to understand information and communicate their decision.¹¹ However, there was no provision in the law to ensure that these communication supports were *unbiased*. This left open the possibility for abuse; a caregiver might relay false messages claiming that their charge wanted to die. And while the law did not permit people to make advance requests for euthanasia (i.e., in case they risked losing decision-making capacity before reaching the point where they were ill enough to qualify to make the request), it called for studies to be done examining expanding the law to include requests made in advance, as well as into other areas.¹² These studies were released in December 2018¹³.

When the law was passed, medical professionals objected to some provisions. First, they argued that the requirement that death be “reasonably foreseeable” was too vague to be properly applied. They believed it might be discriminatory, by virtue not of singling out disabled people as compared to healthy people for aid-in-dying, but for allowing *too few* disabled people to access it. They asked: was “assistance in dying” only for those whose condition would eventually cause their death?¹⁴ Last fall, the Quebec Superior Court found the standard so restrictive as to be unconstitutional, since disabled people without terminal illnesses were not given an equal opportunity to end their lives. Parliament was once again told to craft a bill.¹⁵

The result of this revision, Bill C-7 was introduced this year, but

is on hold at the time of writing due to the coronavirus pandemic. One reason for assisted-suicide opponents to be glad for the revision is that, despite the initial law requesting it be studied, a “mental illness” is not considered a disability under the bill, despite the continued use of the term “psychological suffering.”¹⁶ Thus, mentally ill people are not at risk of being coerced into or improperly given aid-in-dying.

However, the new bill includes even more causes for concern. Firstly personal care providers can now serve as witnesses for euthanasia applications, and only one witness is required for a euthanasia application.¹⁷ This is concerning because many people with disabilities rely on personal assistants and caregivers. What if an abusive caregiver signed off on an application that they coerced someone into completing? This being allowed, and the removal of the requirement of a second witness as a safeguard, makes abuse even more likely. Further problems arise with the two-track system that was created in order to deal with the issue of what constituted a “reasonably foreseeable” death. Even though it gives no definition of a reasonably foreseeable death, the new law divided people seeking euthanasia into those whose deaths are reasonably foreseeable and those whose deaths are not. For those whose deaths are considered foreseeable (whatever that means), the 10-day waiting period is removed,¹⁸ thus removing a potential safeguard against people acting out of rashness or extreme distress. Also, advance requests for euthanasia are now allowed. Specifically, people are no longer required to give consent at the time of euthanasia if they arrange for the procedure to take place “on a specified day,” and do not communicate “by words, sounds or gestures, refusal ... or resistance to its administration.”¹⁹ For those whose deaths are *not* reasonably foreseeable, up to 90 days can pass between the initial medical assessment and euthanasia procedure, but the medical practitioner can shorten this time if the person risks losing decision-making capacity.²⁰

Further concerns appear on examining the newer bill, beyond the changes in timing and in who can serve as witnesses. First, the law specifies that one of the two medical professionals certifying the euthanasia request must have “expertise in the condition that is causing the person’s suffering.”²¹ There are a few problems with this phrasing. Since the professional evaluates their own level of expertise, there is no way to confirm it. And even if the medical professional is an expert in the medical condition the person has, that condition itself may not be the cause of the person’s suffering. Many disabled people also have limited life choices due to lack of affordable and accessible housing, a shortage of home-based assistance, and poverty.²² There is a danger, then, that a disabled person could be suffering because of some life circumstance other than their disability or health condition, but rather than that cause of suffering being remedied for them, their disability could be seen as justification for euthanasia without that other problem ever having to be addressed. Furthermore, while the bill states that “counseling services, mental health and disability support services” must be offered and the person must be informed of “available means to relieve their suffering”²³ other than death, there is no guarantee that the alternate supports discussed will be enough to meet the person’s needs, or will be provided at all. In other words, the bill appears to provide people with support options other than death, but does not go far enough to ensure that these alternatives are ad-

equated. The assumption in the bill still seems to be that death will be the best recourse for the person.

This is just a brief overview of why this law is so problematic. Like much of the world, Canada has come a long way in recognizing and upholding the rights of people with disabilities. Yet disabled people are still a long way from being able to participate equally and fully in society. These laws demonstrate that the country is doing more to provide its citizens with so-called equality in death than helping them to thrive in life. This gap in its efforts should be a blemish on its reputation.

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Can Disability Be Explained By a Model?

By Stephanie Hauer

Human beings love to categorize things, and it's very common for us to arrange things into dichotomies. Even if things are not truly opposites, we tend to position them as such, like cats and dogs, or chocolate and vanilla. But more and more, we're realizing that this method of sorting does not always accurately reflect the world we live in.

Such is the case for disability. It's not as simple as "disabled" or "not disabled." Like many other things in our world, disability is more complex and nuanced than just "yes" or "no." There are a few different ways to define disability, which reflect different schools of thought about it. For example, the Americans with Disabilities Act defines disability as "a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment."¹ The most prominent models of understanding disability are the medical and social models, but there are others, including the diversity model, economic model, and affirmational model.²

The medical model of disability looks at disability as a problem of the individual.³ This way of thinking believes that disability is a result of a physical condition, and therefore intrinsic to the person's body. Thus, it will focus on understanding the condition from a clinical perspective, and seek to treat the condition or its symptoms so as to mitigate its impact. The medical model demonstrates compassion by offering health care and related services to cure the disability or increase the functionality of the person, allowing them to live a more "normal" life.

The medical model has its weaknesses. It risks dehumanizing a person by seeing their disability as the most important part of their

identity. It also puts a lot of burden on an individual person, requiring them to seek (and pay for) health care and services in order to mitigate their disability. This burden is manifested in any number of other ways, because the responsibility to modify activities or functions is placed on the individual for all circumstances. The person must ask for accommodations, because they are viewed as the exception to the rule. The world is not built for them.

The social model of disability, by contrast, looks at disability as a problem with society. This way of thinking posits that our societal structures contain barriers or obstacles that prevent certain people from fully participating. Systemic barriers, negative attitudes, and other forms of exclusion are considered to be the cause of the disability.³ This means that the "problem" is not in the individual, but in the way society is built. Compassion in this model looks like making changes to society that promote accessibility and inclusivity. An example of this would be building a ramp and wheelchair-accessible entry to a building so that people using mobility devices such as wheelchairs or crutches, and people who are walking without such devices can use the space.

The weakness of the social model is that it can be too general.⁴ By focusing on society as a whole, it is easy to overlook the need for individual attention. Some conditions do require medical intervention to reduce risks of complication. The social model of disability is not suited to catching and resolving those types of issues. Other conditions also include internal symptoms that cannot be solved by addressing society's attitudes and systems, such as chronic pain.⁵ Additionally, instituting widespread changes to society takes time, and does not mitigate the real and immediate impacts of disability in daily life before those changes take effect.

Even if societal changes can be instituted quickly, some disabilities are mitigated by accommodations that exacerbate other disabilities. For example, people with sensory processing differences may need to receive auditory input at a lower volume, but people who are hard-of-hearing may need to receive auditory input at a higher volume. It is not possible to both reduce and magnify the volume within a single space simultaneously, so the cumulative accessibility of the space is limited. As problems like these of accommodating multiple disabilities are considered more frequently, innovative solutions may be presented that can address the varied and diverse needs of differently-abled participants, but in the meantime, it is difficult to create a totally accessible space.

Both the medical model and the social model of disability have strengths and weaknesses, so people often develop their own nuanced understanding that pulls from both schools of thought. For example, the social adapted model of disability acknowledges that while a person's innate disability may limit them, their environment can be just as limiting — if not more limiting — than the inherent effects of the disability itself.²

But what do all these models mean on a practical and personal level? I include myself in the question about “personal level.” When it comes to my own life, I can never figure out if I'm actually “disabled” or not. I have four diagnosed chronic illnesses. I take several prescriptions every day in an attempt to reduce my symptoms. Even with those medications, I still have to modify certain tasks or activities to avoid aggravating my conditions. But some days are better than others, and even my bad days don't prevent me from living my life fully independently. Where do I, and others like me, fall in terms of all these models and theories?

The World Health Organization says “disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.”⁶ By that definition, it seems that I count. I have an

impairment in that my autonomic nervous system cannot properly regulate my heart rate. I have activity limitations in that it hurts my joints to do basic tasks like brushing my teeth, braiding my hair, or writing by hand. These things affect me in many different life situations, sometimes preventing me from being involved in activities altogether. It is not uncommon that I have to say “no, I can't do that, because of this condition I have.”

And yet, it feels strange for me to say “I am disabled” or “I have a disability.” My mind immediately tries to resist that label — why? Because disability is heavily stigmatized. We have all been raised with some degree of ableism, and we've all internalized some amount of it. It takes ongoing work to unlearn those biases and stigmas. There is an association of disability with helplessness, but that's a false correlation. I can't do some things, but I can do others, and even if I couldn't, that wouldn't detract from my value as a person.

We are not defined by our ability to work or accomplish specific tasks. We don't get bonus points just because we can do certain things. We are each entirely unique human beings, living lives that matter, regardless of our abilities. Whether disability is rooted in medical diagnosis, in social barriers, a combination of the two, or something else entirely, one thing remains constant: that our dignity and value is inherent and permanently rooted in ourselves and our humanity.

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Insecurity

By Sophie Trist

A restaurant needs three things to receive a five-star rating from college students: it must be near campus, it must be cheap, and its food must be delectable enough to provide comfort when you fail a test, flub an audition, or just want to procrastinate on homework. For my best friend Alex and me, Taqueria Corona fulfilled all of these vital functions. We went to the Mexican place at least once a week. The air was laced with the familiar smells of freshly-baked tortilla chips and the tang of salsa. Spanish music provided a low undercurrent of sound, almost but not entirely drowned out by the laughter, chattering, and clatter of other diners. This September night started out like any other, with Alex and I taking seats at our usual back corner table and me leaning my cane against the wall where it wouldn't trip anyone.

We were catching up on the latest school happenings when the waiter came to our table. "What would you like to drink?" he asked Alex.

"Iced tea," Alex replied, as always.

A slight pause, then the waiter asked, "And what will she be having?" I ground my teeth in frustration that was all the more irritating because it was familiar. Not this again.

"I don't know," Alex said. "Ask her."

"I'll have iced tea too," I said, careful to keep my tone polite and cheerful. *He doesn't mean anything by it*, I told myself. *Getting angry would just ruin his day, and nobody wants that. Besides, I don't want him going away with the impression that all blind people are crazy and start yelling at the drop of a hat.*

"That's so stupid," Alex said as the waiter left. I nodded, not being able to speak due to the fact that I was eating a large chip loaded with salsa.

Once I had swallowed the deliciousness, I said, "Sometimes I want to wear a t-shirt that just says, don't be afraid to talk to me because I'm blind. I'm not a dragon or anything. I only breathe fire when I don't get enough sleep or food."

"It's like they think just because you can't see, you're, like, five or something," Alex said, his voice rising in frustration.

"Thanks for not speaking for me," I said. "I hate it when people do that." It was refreshing to have a sighted person share my

frustration at being patronized. A lot of my family members, as loving and well-meaning as they are, don't understand why I get so annoyed when strangers talk to them instead of me because they think I'm incapable of making and/or executing my own decisions. I think part of it is that, unlike Alex, they've known me since I was three and would have ordered cake and ice cream for dinner if given the chance. And they still sometimes see me as that child, and so speaking up for me is automatic, unconscious.

"Does stuff like that happen often?" Alex asked. I appreciated his frank curiosity. Most people are afraid to ask me questions about my blindness, afraid they'll offend me.

"Not super often," I said. "What I tend to get are the awkward silences. When I'm by myself and there's no sighted person for them to address, they don't know what to say."

My mind flashed back to a piano competition I took part in when I was thirteen. Once I finished playing my two pieces, the judge stayed silent for several moments before saying, "Um, I've never heard a, uh, an unsighted person play before." I bit my lip to keep from laughing so I wouldn't embarrass myself or the judge. Unsighted? Really? She acted as if "blind" was the equivalent of the F word, like I would melt upon hearing it.

I was in the middle of telling Alex this story when the waiter came back, drinks in hand. "Do y'all know what you'll be having tonight?" he asked.

"I'll go with the chicken enchiladas," I said.

"Coming right up," the waiter said easily.

Alex ordered his food, and the waiter walked back toward the kitchens. I felt pretty good about the whole encounter. Hopefully, our waiter wouldn't have the same mentality when he met another disabled person. I knew this wouldn't be the last time something like this happened to me, but I refused to let such thoughts ruin dinner. The conversation shifted, and Alex and I started rehashing one of our oldest and friendliest arguments, a debate that must have raged between English majors and theater nerds since the beginning of time: whether books or musicals were superior.

The scene in Taqueria Corona was the last thing on my mind on the January morning when I entered Reagan Airport with eight other Loyola students after participating in my first March for Life.

By the time we reached the airport, I was so tired that I probably wouldn't have noticed if a horde of aliens mounted on unicorns had descended from the heavens and announced their plans to conquer the world. After four days of late nights, early mornings, little food, and constant standing, I probably would have shrugged and told the aliens that as long as I could get some sleep in my own bed before world domination began, I was good with that. We were at that strange level of tiredness where we wanted desperately to sleep but were also deliriously hyper.

As we proceeded through the line to check in and check our bags, I pulled out my wallet and rummaged through it. "Is this my ID?" I asked Alex. All of the cards in my wallet were usually labeled in braille, but I'd received several name tags and other cards during the trip and wanted to make sure I had the right one before confronting the TSA, which I affectionately referred to as the Terrible Sociopaths of America. Give me an acronym, and I will feel duty bound to create a naughty or twisted version of it.

"Yeah," Alex replied, and I put the card in my coat pocket.

I was the last of the Loyola crew to face the airport Gestapo. I walked up to the desk, pulled the card out of my pocket, and handed it to the employee.

"Did you have a good trip, ma'am?" the TSA guy asked.

"Yes sir," I said.

"Headed home?" the guy asked.

"Yes sir, back to New Orleans," I said.

"Here you go. Have a nice flight," he said, handing my ID back. I put it back in my pocket and walked through the metal detector unscathed, living to travel another day.

When I got through security, the first thing I heard was Alex laughing his head off. As a rule, we both laughed a lot, but this level of hilarity was rare, even for us.

"Dude, what is wrong with you?" I asked, starting to laugh myself.

"Oh my God, Sophie, you just handed that man your metro card," Alex said.

"Are you kidding me right now?" I asked. "Did I just get through security with a freaking metro card?"

"Yes," Alex said, laughing so hard he could barely talk. I reached into my coat pocket, and sure enough, there was my Louisiana ID. I hadn't realized the metro card I'd been using to get around D.C. was in the same pocket, and because they felt exactly the same, I'd pulled out the metro card. The TSA employee hadn't said a word. So much for them being the airport Gestapo.

For the next five minutes, I literally could not stop laughing. When I tried to speak, all that would come out was more snorts of mirth interspersed with unintelligible words. Alex and I somehow got to our gate, staggering against each other as we cracked up.

Finally, I managed to say, "You know, this doesn't exactly fill me with faith in our national security. I mean, I could be the leader of ISIS for all they know."

"I doubt that. You're totally blind, five-feet nothing, and you weigh less than a hundred pounds," Alex said. True, true, and... very true. I was pretty sure I had some elf DNA buried somewhere

in my gene pool.

"I could have had plastic surgery," I said. "Besides, who says blind people can't be terrorists? People would never suspect us. I bet we could blow up a lot of stuff before anyone caught on."

I spent the time before our flight departed texting my family, my boyfriend, and all my blind friends about what would forever be known in the annals of SophieLand as "the TSA story." Everyone thought it was hilarious. My friends still laugh about it, and this year, Alex and I acted it out (did I mention he's a theater nerd?) on the eve of our second trip to D.C.

It wasn't until months later that I felt the sharp side of the double-edged sword of the TSA employee's kindness. By letting me through security with a metro card, he was telling me that he didn't take me seriously. If he did, he would have asked me for my ID, and I would have pulled it out with an apology and an embarrassed smile. I wouldn't have flipped out or burst into tears. To him, just like to the waiter in the Mexican restaurant and all the other strangers who look at me and see nothing but my cane and prosthetic eyes, I am a child, not a woman as capable as any other of both good and bad. If people don't believe I can be a threat to national security, do they believe I can teach college students, write a *New*

York Times bestseller, or raise children of my own?

Some nights when I can't sleep, I wonder if there's anything I can do to keep strangers from underestimating me. Is it the way I walk? The way I talk? The fact that I'm petite? Sometimes I feel the weight of all the world's blind people on my shoulders, urging me to be a good ambassador of our race. Then I silently scream, raging against the unfairness of being made to repre-

sent a group of people as diverse as any other, like an animal at the zoo. The only thing we all have in common is that our eyes don't work. Some blind people use canes, others use guide dogs, it's just a personal preference. Some, like me, are into fantasy books and country music, while others are passionate about sports, fashion, or old cars. We are people in every sense of that word. We can't be reduced to one stereotype, one representative for all. I'm just as complicated as any sighted person, and I have a deep, DEEP appreciation for people like my family and my friend Alex who understand that simple, all-important truth.

Most days, I'm able to push these insecurities to the back of my mind and go through life laughing, singing, and eating Mexican food. Most days, I know that strangers who patronize me don't do it out of malice, but because of their own deep insecurity and fear of a kind of life they don't understand. But other days, I wonder how many more times people will speak to my sighted companions instead of me as if they're my handlers, how many more times people won't take me seriously, and if their ignorance will have more serious consequences than me foiling airport security with a metro card.

It wasn't until months later that I felt the sharp side of the double-edged sword of the TSA employee's kindness. By letting me through security with a metro card, he was telling me that he didn't take me seriously.



Should We Pursue Cures for Disabilities?

Rehumanize International (and by extension, *Life Matters Journal*) is dedicated to ending aggressive violence against human beings. There are myriad acts of aggressive violence that are addressed in this magazine because of that central principle. However, there are also issues which fall in the periphery of the causes for peace and life; on these topics, Rehumanize International does not take an official stance, but we still find them important and worthy of discussion. This section of *Life Matters Journal*, "Opposing Views," aims to highlight varying perspectives on such issues.

Affirmative

By Kelly Matula, PhD

I don't believe that the desire for or pursuit of cures for disabling conditions is inherently wrong or necessarily represents internalized ableism. Critics of the idea of curing disability often emphasize disability as an identity of which people should be proud. I see much good in the concept of disability identity: I would not be the person I am today were I not disabled, and I am a proud disabled person. However, I also see the notion of disability identity as complicated, since other characteristics people claim as identities, like gender or race, do not intrinsically involve deficits in physical function or health that often result in physical suffering. Some disabled people completely reject this type of medical model, seeing disability as purely social, but others do not. I believe that both models contain some aspects of the truth, and how much medical or social factors are causing difficulties can vary from person to person, and for a given person across situations or their lifetime. Thus, I think that neither being interested in cures for one's disability, nor rejecting cures and focusing on identity, is the inherently "right" way to be a disabled person.

Some people fear that the pursuit of cures detracts from efforts to combat ableism and increase accessibility. I believe this is false: just because someone is interested in a cure for their own disability doesn't mean they don't care whether other disabled people — or they themselves, before the cure can be found — have jobs or accessible housing. People can and do work toward both goals. Any work on cures or treatments for a given disability does have to be done carefully, to ensure no one is pressured to be cured and that the pursuit of cures does not unintentionally foster ableism. But I think it is possible to balance these concerns. Thus, while I don't believe cures should be forced on anyone, I don't think the pursuit of cures, or individual disabled people who want to pursue them, should be stigmatized.

Negative

By Beth Fox, MPH

First a caveat: I think there is great merit in fighting for cures for aspects of disabling conditions, particularly those that limit life expectancy. However, believing that disability needs to be cured can start you descending down the slippery slope of questioning the quality of life of those with disabilities, and this can lead to the toxic belief that it is better to be dead than disabled. While not all advocates for cures hold this belief, it is important to recognize the possible progression. Instead, it is best to follow a social model of disability which appreciates our genetic diversity. This stance allows us to see two crucial things that the search for cures misses.

First, everyone has a unique set strengths and weaknesses. It is society that dictates which of these weaknesses qualify as disability. For those with disabilities, some of their strengths are directly related to their weaknesses. We see this clearly in the co-occurrence of autism spectrum disorder and savant syndrome. However, this is seen in even more mundane actions. Being blind, I am exceptionally good at finding things in the dark, as I have learned to utilize my other senses. Similarly, Deaf individuals tend to have greater expertise in recognizing faces and non-verbal cues, even when they occur in the periphery.

Secondly, many of the challenges we face as disabled people are due to the society and environment we live in. If we lived in a truly accessible and inclusive world, disability would not matter. If every building had ramps and elevators it wouldn't matter that I can't climb stairs. My disability is a part of me just like my race and my gender. It is not a problem that needs to be solved any more than those are.



Assisted Suicide and the Disabled: One Disabled Person's Perspective

By Sarah Terzo

Many well-meaning people in our country support assisted suicide. They may tell themselves, “If I was terminally ill, or senile, or unable to care for myself, I would not want to be forced to live in that situation. I would want to be able to escape from that kind of life. Therefore, assisted suicide should be legal.” But they don’t realize that assisted suicide is a huge threat to one segment of the population- the disabled. What we see happening in other countries that have legalized assisted suicide, and to a lesser extent in the U.S., is alarming.

ASSISTED SUICIDE FOR THE DISABLED AND CHRONICALLY ILL

Currently in the United States, under normal circumstances, if someone wants to kill themselves, the police can be called. If the police fear a person is about to kill themselves, they will take that person into custody and bring them to a mental health facility. The police will forcibly intervene to prevent the person’s suicide. The suicidal person will be interviewed at the facility. If mental health workers fear they’re in danger of suicide, the person will be hospitalized. They won’t be released from until they can convince mental health professionals they won’t die by suicide. However, in many places, a suicidal person who is also disabled or chronically ill might be treated very differently.

Countries such as Belgium¹ and the Netherlands² allow euthanasia or assisted suicide for people who experience incurable, unbearable suffering, including mental suffering. Canada has also started allowing non-terminally ill people to kill themselves. Such laws enable the suicides of people with physical and mental disabilities or illnesses. People have been killed or assisted in killing themselves because of conditions such as combined deafness and blindness³; autism⁴; and alcoholism.⁵ A study documented 37 cases in the Netherlands⁶ where people with mental health problems were enabled to die by suicide after refusing treatment that could have helped them. People with disabilities or other severe health problems are being assisted in dying rather than living.

The United States hasn’t yet reached this point, although seven states and the District of Columbia⁷ allow assisted suicide for people diagnosed with terminal illnesses. Such laws devalue the lives

of one particular class of ill person but don’t (yet) go as far as certain European laws. Even these laws create two classes of people—those whose suicides should be prevented and those who should be helped to kill themselves. In this way, they devalue the lives of people with serious illnesses by relegating them to a category of people whose lives aren’t worth fighting for. This also happens with disabled people. And, it should be noted, every country I have mentioned started out only allowing assisted suicide for the terminally ill before broadening the definition to include others suffering from chronic, but non-fatal physical or mental illnesses and disabilities. Once respect for life is broken down—once it’s determined that some lives are not worth living and not worth saving—the society starts traveling down the slippery slope. When society determined that terminally ill people should be removed from the category of those with valuable lives, it was only a small step to include those with chronic illnesses and disabilities. After all, they are suffering too, right?

As a disabled person, I might not currently qualify for assisted suicide here in New Jersey because my illness — rheumatoid arthritis — is not usually terminal (though it can lead to premature death, and it could become terminal if the disease starts attacking my heart or lungs, which would make me eligible). However, people with my condition and other disabilities have been victims of illegally assisted suicides in the United States.

Jack Kevorkian, known as Dr. Death, killed 130 people who wanted to die by assisted suicide. Some were terminally ill, but others had chronic but nonfatal conditions.⁸ One woman⁹ had my diagnosis — rheumatoid arthritis. Despite killing 130 people over the course of his career, Kevorkian served only 8 years in jail. Would a person who killed 130 able-bodied people get off so lightly? What serial killer who killed 130 people would serve only eight years? Apparently, one who kills only disabled people.

A SUICIDE PREVENTION GROUP SUPPORTS SOME SUICIDES

Another disturbing sign is how the American Association of Suicidology (AAS), a suicide prevention group, now accepts the legitimacy of assisted suicide for the terminally ill. It takes a disturb-

ingly vague stance on more permissive assisted suicide laws. AAS released a paper last fall declaring that “legal physician-assisted deaths should not be considered to be cases of suicide.” Therefore, they won’t work to prevent the suicides of people who are legally allowed to kill themselves.

All these conditions — laws allowing euthanasia and assisted suicide, especially the permissive laws in places such as Belgium and the Netherlands, the lax treatment of Kevorkian, and the acceptance of assisted suicide by a supposed suicide prevention organization — show how the lives of disabled and non-disabled people are not valued equally.

THE BURDEN OF BEING A BURDEN

Disabled people are vulnerable to being coerced into suicide. Many disabled people fear being a burden to others (of the 1,275 people who have died through assisted suicide in Oregon, over 40% cited¹⁰ “Burden on family, friends/caregivers” as being a concern). They know their disabilities can make life harder for the people who love them. They know their medical care is costly.

I am constantly aware of how much my physical illness causes burdens to my family. My mother has to come to my house several times a week to help me shower. She has to do this despite working full time. It is deeply inconvenient for her. She also has to help clean my apartment. It is a burden on a 71-year-old woman I love that I wish she didn’t have to bear. Normally I would have a home health aide to do these things, but this is suspended due to COVID.

Many disabled people need even more help than I do from friends and family. It is very easy to feel guilty about this, even when the person doing the helping is gracious. When the person doing the helping is abusive (a situation that is all too common) the shame of needing help can be even worse. It isn’t hard for me to see how the shame and sadness of needing help from loved ones could make a disabled person suicidal. The desire to set a loved one “free” from the burden can be an incentive to suicide for a disabled person, just like a terminally ill person.

But is this really a good reason for suicide? It is, apparently, good enough in Oregon. But I wonder. If a healthy, able-bodied college student went to a counselor in Oregon and said she felt like a burden on her family because of the high cost of her education, would she be approved for assisted suicide? The answer is certainly no both here and abroad. Yet disabled or ill people are approved for suicide on these grounds regularly. Clearly, there is a double standard here, with some lives being more important than others.

SOME PEOPLE ARE JUST TOO EXPENSIVE. SUICIDE TO THE RESCUE

Then there is the cost of the medical bills that caregivers or families may be forced to pay. And, of course, resentful family members, tired of spending money on Grandma’s health care, could easily coerce her into suicide. In current law, there are few safeguards preventing this. Especially when suicide consultations are done over telemedicine with family members present. In these cases, terminally ill people can be put under enormous pressure that is undetected by doctors.

Cutting costs in our for-profit medical system is always a factor. There have been documented cases where health insurance would pay for suicide pills, but not chemotherapy for cancer patients. Would you want to face a situation where your cancer treatment was refused but your doctor offered free suicide pills instead? This is currently a reality for some patients in California and Oregon.

Dr. Brian Callister worked in a hospital with cancer patients. He was taking care of two patients. He was of the opinion that neither patient was terminal and could recover with treatment. But they needed procedures that were not performed at his hospital. To get these procedures, he needed to transfer one to California and the other to Oregon— two states with assisted suicide laws.

When he sought permission to transfer them from their insurance companies, both insurance companies refused to cover the procedures¹¹ and the transfers. Instead, both recommended and offered to cover assisted suicide drugs. Both these patients were refused life-saving treatment due to its cost and instead given suicide as their only option.

According to the article:

The phone calls took place last year within the span of a month, Dr. Callister said. He said he did nothing to prompt the suggestion of suicide pills. in either case.

The patients were not terminal, but “would have become terminal without the procedures.”

“It was estimated that their chance for cure — cure, not just adding time — of about 50 percent in one case and 70 percent in the other case,” Dr. Callister said.¹²

It is inevitable that health insurance companies, which operate for a profit, will want to save money. And money can be saved by refusing expensive treatment and covering the much, much cheaper cost of suicide.

In another case¹³, a chronically ill mother of four, who was classified as terminally ill but still had time left to live, was told by her insurance company that they would no longer cover her pain medication, her chemotherapy, or her oxygen. In distress, she asked them what she could do. They responded that they couldn’t tell her what to do. But they told her they would cover suicide pills for a copay of \$1.20. She says:

I can’t — can’t describe what it feels like when someone tells you that they’re no longer going to pay for drugs that will extend your life significantly, that’ll give me more time with my kids, and my family, and all these adventures we haven’t gone on yet. But for a buck I can go ahead and make it stop if I kill myself...

without money, without jobs, without these things, there’s absolutely no way I could have any kind of comfort care treated. My only option would be to suffer with no medication, or to pay a dollar, with my kids around me, and watch me give up.

And I do understand that that’s what some people want. There is so much fear. There is — there are really painful days, and it gets scary. But those days also make the good days great. When I can wake up and I’m able to do things, I’m able to experience so much more with my family and

friends. That's because I know what tomorrow might bring. And that's something that I wouldn't wish on anybody, but it's also something that I'm very thankful for. It, ah, it changes how you look at everything.¹⁴

Fortunately, this woman was able to go into a hospice program and at least get treatment for pain. To rob a person of pain medication and force them to live in agony unless they "choose" suicide is a truly evil act. But this situation is a reality for people in this woman's situation.

Disabled people cost money to keep alive. Through Medicaid, my medical care, which I would die without, costs the government over \$5000 a month. Calculate that amount over a lifetime of care, and you can see how my suicide would save our government an awful lot of money. Because of insanely high healthcare costs in this country, this is the case for most chronically ill and disabled people. Disabled people also need expensive accessibility projects and products. Assisted suicide of those who are a financial burden can be seen as eliminating government spending and cutting health care costs. It is naive to think that our medical establishment, and our government, can't make that connection.

With the high costs of medical care and our profit-driven medical system, is there any way assisted suicide will *not* be coercive?

SENDING A MESSAGE

When suicide is given legal sanction, it sends a message to the public. It sends a message to many people with chronic illnesses and disabilities that their lives are not worth fighting for. I have experienced this in my own life. For a long time, I had a difficult time writing or reading about assisted suicide because it made me feel devalued. Knowing that many people, particularly abroad, felt that my life is not worth living and my suicide should be aided, not prevented, made me feel bad about myself and my situation. It makes me feel more vulnerable to the suicidal feelings I still occasionally have. It is an emotional struggle to deal with this issue.

Because sanctions against suicides have broken down, and because of the well-known phenomenon of suicide contagion,¹⁵ it's not surprising that since assisted suicide has become more widespread, suicide rates in this country have risen. There can be many reasons for this, of course. But states with assisted suicide laws have higher rates of "regular" suicide than states where it is still illegal. For example,¹⁶ Oregon, the first state where suicide was legalized for chronically ill people, has a suicide rate 43% higher than the national average.

MENTAL HEALTH TREATMENT: DISABLED VS. NON-DISABLED

There is another question that plagues many disabled people when thinking of assisted suicide. Will we get the same suicide prevention treatment as able-bodied people? This fear affects me in my own life. As someone with bipolar disorder in addition to a physical disability, I've fought strong suicidal thoughts in the past. They are a symptom of bipolar that nearly all people with the disorder get from time to time.

In the past, before I developed rheumatoid arthritis and could no longer walk normally, doctors forced me into treatment and

prevented me from dying by suicide. Now, twenty years later, I am deeply grateful.

My bipolar disorder has been in remission for a while and my suicidal thoughts far less prominent, though not completely gone. However, if I did have another depressive episode, I would want suicide prevention services. But will I get them now that I'm in a wheelchair? There are advocates of assisted suicide who would instead give me help to end my life.

Does this actually happen? Do disabled people get treated differently when they go for suicide prevention treatment? The answer is yes.

Claire Freeman¹⁷ is severely disabled, unable to move her arms and legs. Her condition is the result of a diving accident she suffered as a teenager. She is a wheelchair user like me. She is in constant physical pain, just like I am. She went through a long battle with clinical depression during which she attempted suicide four times.

While in the hospital after one of her suicide attempts, she talked to a psychiatrist. That psychiatrist talked to able-bodied suicidal people all day long. He gave them medication, therapy, and encouragement not to take their own lives. He fought for their lives. But what did he tell Claire?

Claire told the doctor that she wanted to die and asked about assisted suicide. According to her, the doctor said, "That could be an option for you." She says:

So we had a chat and he talked about Switzerland and about what's happening in other parts of the world.

So I started putting things together to do that. I was in constant pain, while still trying to work and build a house and all sorts of things.¹⁸

She left the hospital, equipped by the medical staff there with information about how she could travel to Switzerland and end her own life. The other able-bodied patients in the same hospital were not released until they could convince doctors that their suicidal feelings were under control and they would *not* die by suicide, but Claire left with a suicide plan given to her by the doctor and sanctioned by the hospital.¹⁹

The story could easily end how it often ends, with the suicide of one more disabled person. But it didn't. Claire suffered from a severe medical setback when an operation to replace metalwork in her neck failed, which forced her to do the one thing she had refused to do in her hectic life- rest:

I started to sleep, and the pain started disappearing," she said. "I know from my own personal experience that a lot of my pain was related to the stress and the hectic lifestyle and the way I kept on just pushing myself and my body."²⁰

While recovering from the operation, Claire started a blog and built a following on social media. She discovered a new purpose in life- helping other disabled people and advocating for herself and others. Even though she was left even more badly disabled than before, Claire decided she wanted to live. Since then, she has worked as a model, built up a large following on Instagram, started helping other disabled people who are suicidal, and earned a doctorate de-

gree from the University of Toronto.²¹

Despite her disability, she lives a full, relatively happy life, though not one without challenges — a thing that is within reach for the vast majority of disabled people.

She has learned some lessons. She says:

I realized that a lot of the advice I had been given, like from the psychologist and from a psychiatrist who saw me after an earlier suicide attempt, was because they were looking at me and just seeing the disability.

They were not saying, ‘Hey, what’s going on in your life? Are you working too much? Are you in too much pain?’²²

None of those questions were asked, it was just, ‘Of course, she wants to die, she’s in a wheelchair, she’s in pain.’²³

“QUALITY OF LIFE”

Disabled people bear the burden both of the emotional ramifications of assisted suicide and the way it influences those in the medical profession and those in the public. Many people don’t see the value of living a life as a disabled person. They think it is a “poor quality of life.” That argument has been used to justify the deaths of so many disabled people! Able-bodied people say “I would never want to live in a wheelchair.”

A friend of mine, who is wheelchair-bound, was encouraged to sign a DNR (do not resuscitate) order in the hospital because doctors thought she would have to be permanently on a respirator. “You don’t want to live like that,” they told her.

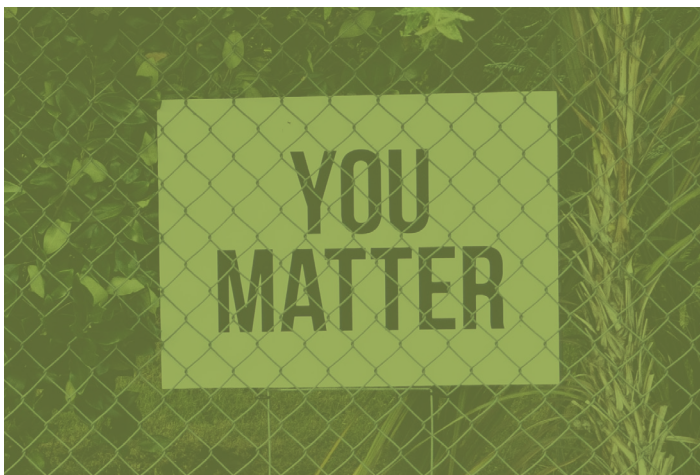
Well, she refused to sign the order, got her respirator, and has since graduated from college, which she attended full time and in person. Before COVID, she traveled and gave a speech at a convention on ableism in medicine. She is living a fulfilling life, in her wheelchair, with her portable respirator. She asked the audience at the conference where she spoke, “Who would want to live in on a respirator?” She raised her hand, “Me!”

Despite my constant pain, limited ability, and dependence on others, I agree with her that my disabled life is worth living. And if I ever lose hope, I hope there will be people around me to remind me that my life is meaningful, productive, and valuable and that I am loved by friends and family. I hope I am protected from those who would take advantage of my vulnerability and encourage me

to take my own life.

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Blind Author Kristen Witucki on Parenting with Disabilities

By Kelly Matula, PhD

I had the pleasure of interviewing my friend Kristen Witucki for this issue. Kristen, who has been blind since birth, is the author of two books, *The Transcriber* and *Outside Myself*. She also serves as the curriculum and content editor for Learning Ally's College Success Program and teaches blind students. She lives in Highland Park, New Jersey, with her husband, who is also blind, and three children, who are sighted. Below, read our discussion about her experiences as a disabled parent:

LMJ: When you were growing up, what were some of your beliefs or thoughts about blindness and parenthood? Did you know older blind people who were parents? Did you have the impression people thought you would be a capable parent?

KW: I did not know any blind parents when I was a child. In fact, I think part of the reason I wanted to have children so badly was that it was understood, though never exactly discussed, that I would not be hired to babysit other people's kids, because I could not see. Maybe that encouraged me to be a teacher and a parent, because I wanted to prove I could do it. Maybe that made me extra naïve. But having children has been the greatest reward and the greatest challenge of my daily life.

LMJ: When you were pregnant, in what ways did you find people treating you or your husband differently than normally-sighted or other non-disabled parents-to-be were treated? Were all the differences negative, or were there some positive ones, even if they came from ableist assumptions (e.g., were people extra helpful)? How did you feel about these differences? How did you handle them?

KW: My friends and family members treated my pregnancy more or less like any other pregnancy. However, I noticed that strang-

ers never, ever mentioned it, even when I must have looked very obviously pregnant, and I always wondered whether it meant my pregnancy felt taboo to them. I'm an introvert, so normally I don't like when people get very excited about me, but I have to admit that I was ridiculously happy one day when one woman on the train congratulated me effusively on my pregnancy. I felt like I belonged somehow.

LMJ: People with disabilities often face barriers and ableism in medical settings; did you face these types of issues related to your first pregnancy, birth, and your son's early care? How did you handle these?

KW: When I went for my twenty-week anatomy scan, the sonographer saw a mark on my son's heart which had a weak correlation to Down's Syndrome. When I went to the antenatal unit of the hospital for follow-up care, the doctor there automatically recommended an abortion, because, he said, I was blind and now this child would have additional issues. This was without definite confirmation that anything was wrong. This was extra ironic, because we were in a Catholic hospital, that this doctor thought that my child's life would be so terrible with me that ending it was the answer. Anyway, we came back in two weeks for a follow-up and fortunately we were with a different doctor, and everything was fine.

Before my son was born, we took a tour of the hospital and met many nurses who all seemed great about me being a mother. None of them were there when he decided to show up, and the nurse who took us in was pretty skeptical. I realized how very hard it is to advocate for oneself when one is trying to push a baby out as quickly as possible! My method for handling those types of people was to keep my family around me at all times. That may not have proven

to anyone that I could parent, but we felt that we would be allowed to leave if people assumed my sighted family members were living with us, and it worked.

LMJ: As you had more children and they grew, did you learn anything in particular that helped you better deal with ableism and advocate for yourself and your family? How did people's perceptions of you as a parent change? Did you take advantage of any particular support networks for blind parents or those with other disabilities?

KW: Honestly, the hospital was the only place where I encountered pushback about parenting so far. People who worked in daycares and schools, for instance, both in New Jersey where we lived most of the time and in West Virginia where we lived for a couple of years, assumed we were competent parents. Sometimes strangers do yell, "Take good care of her!" to my son, and I always hope he doesn't notice, though I'm sure he does. I want to yell back, "If they took care of me, we'd all be dead!" But I don't.

LMJ: Have you seen any improvements in society's treatment of disabled parents since you first became a parent? What do you think has caused them?

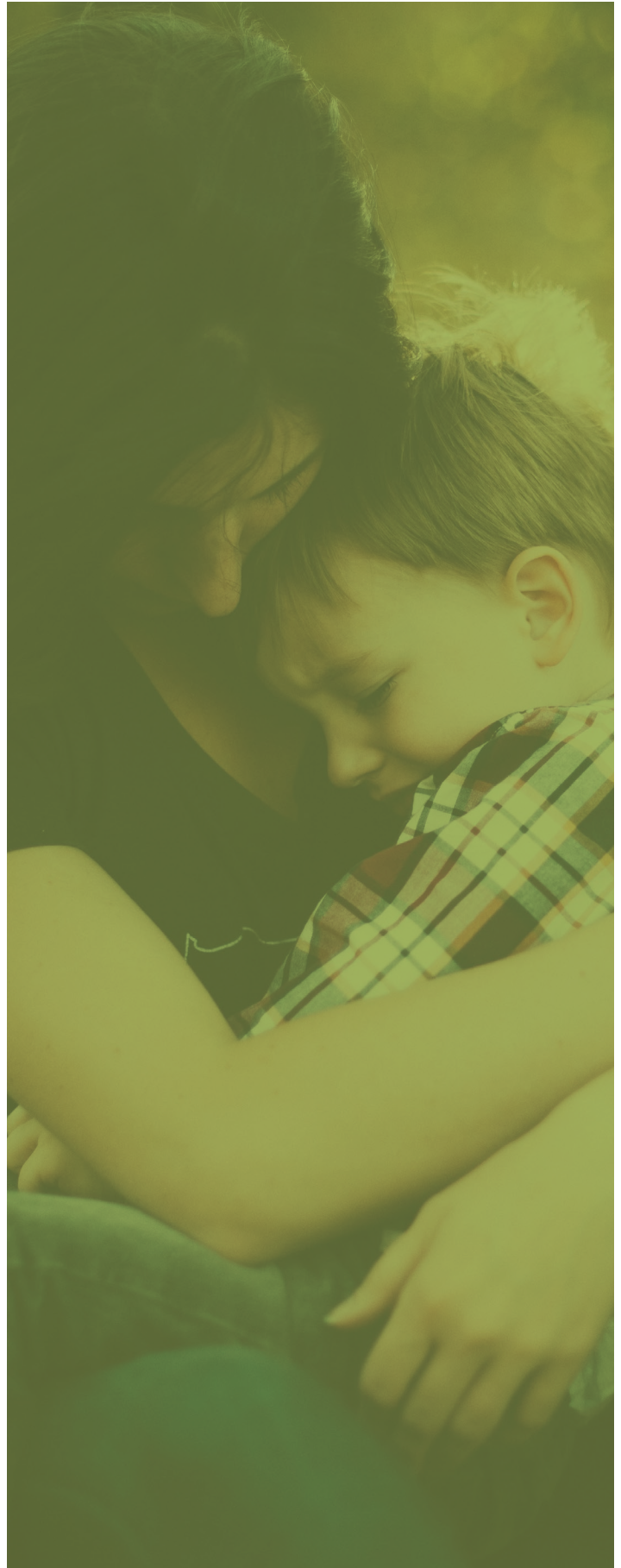
KW: I know a number of states have created legislation that basically says that parents with disabilities can be capable parents and you can't remove a child from a family just because the parents have disabilities. This is definitely a step in the right direction, but I hope it is translated to the many, many people in large hospitals who need to understand it. I had my younger two children at home with the help of certified nurse midwives. They got to know my family and me, and I didn't have to worry about someone new entering the birth picture. So I'm not sure if hospitals have improved or not, and I'm scared to find out!

LMJ: If you could pick the one or two most important ways in which society could change to better respect the dignity and abilities of disabled parents and their families, what would they be?

KW: Respecting people as parents is very similar to respecting them as professionals and humans. If people have questions or are worried that prospective parents can't handle something, they should politely ask how a parent would carry out a certain task. This opens up the opportunity for dialogue, and new parents, in particular, can honestly ask for help with specific tasks that they've never done before without worrying that asking will cause repercussions in the social services sector! Parents should not worry about having their children taken away!

LMJ: If you could give one piece of advice to disabled parents-to-be, what would it be?

KW: I'm not sure I'm the best person to give advice, but if you want to be a parent, your children will look to you to help them to make sense of the world, including any judgments placed on you by ableist assumptions. Be prepared to have these conversations with your children, and probably earlier than you are anticipating they will happen! Other than that, enjoy as much as you can. Parenting involves incorporating the glacial daily time of a myriad of tiny interactions that can wear you out and then the feeling that it all flew. Those feelings combine, so sometimes it can be hard to remember the gift that you have when you are cleaning up the poop. But even looking back on each day or each week to figure out the small joys and accomplishments can make the longer haul easier and can make you a little more patient with the people who say, "Enjoy it all. It flies!"





A Fatal Negligence: Ableism and the Coronavirus Pandemic

By Sophie Trist

As a disabled person living through the COVID-19 pandemic, I often have to remind myself that this isn't the 1940's, and we don't live in Nazi Germany. The rhetoric surrounding disabled people and COVID-19 is frightening and traumatic for many of us. We see armed white nationalist protesters urging America to "thin the herd", declaring that the disabled and immunocompromised are expendable so long as they can get a haircut or go out to grab a burger. In the first weeks of the pandemic, several states issued medical ethics guidelines which essentially declared our lives less valuable than those of able-bodied people, using the Quality Adjusted Life Years (QALY) equation to mathematically justify their ableism.¹ Even in states which have not threatened outright to deny life-saving resources to people with disabilities, we fear that should we contract COVID-19, unconscious ableism within the healthcare system will lead to us receiving subpar treatment because of common misconceptions about the value of our lives. But ableism has manifested itself in many more subtle yet equally dangerous ways during this pandemic. Disabled people have been an afterthought, if not erased altogether, by governmental responses to the virus.

The pandemic is devastating for people with developmental disabilities living in group homes. In New York, disabled adults were still being sent to day programs on March 16, after bars and

restaurants were closed. Additionally, it is difficult for people with profound developmental disabilities to comprehend new social distancing and hand-washing guidelines. For those who cannot speak for themselves, the experience of being hospitalized alone or placed in self-isolation can be even more traumatic because they do not understand what is going on. At a group home for adults with disabilities in Bayville, New York, thirty-seven of the forty-six residents have tested positive for the novel coronavirus. A study conducted by a large consortium of private care providers found that disabled people living in New York's group homes are 5.34 times more likely than the general population to contract the virus and four times more likely to die from it.² In this unprecedented time, family members and disability rights advocates fear that the developmentally disabled, who often live together in crowded conditions, are not being given the resources and protection they need to survive this.

Disabled people are being short-changed when it comes to COVID-19 resources as well. The White House's initial failure to include ASL interpreters at its press conferences has been well documented, leaving Deaf Americans out of the loop when it comes to federal responses to the pandemic. As Melanie Ehrenkranz explains in her brilliant *Vice* article, many blind people cannot access vital updates regarding the pandemic. A lot of news about

COVID-19 is published in the form of charts and infographics that are completely inaccessible, forcing blind people to depend on hearsay and unreliable sources.³ A survey conducted by Markup, a respected web accessibility organization, found accessibility barriers on forty-eight state coronavirus websites. These accessibility barriers include images without descriptive text, missing form labels, and low-contrast text that is difficult to read for visually impaired seniors who are at a higher risk for COVID-19. On North Carolina's website, the number to call if you are showing symptoms of the virus is part of an image, making it impossible for screen reading software to pick up. Only Maine and New Mexico's coronavirus websites were found to be completely accessible to blind users.⁴ Ms. Ehrenkranz is absolutely correct when she calls failure to make critical health information accessible to the blind and deaf "a fatal negligence."

Additionally, America's apparent belief that everyone has access to a car discriminates against disabled and poor people. CVS drive-through sites do not distribute tests to pedestrians, forcing people with disabilities who can't drive to risk their lives by going to hospitals for testing.⁵ Fortunately, disabled people are strengthening our own networks and providing each other with accessible information and assistance however we can, but the systematic failure to consider our needs speaks to a country that was not built with us in mind and an exclusionary mentality that shows no signs of ending.

On October 1, 1977, former vice-president Hubert Humphrey said, "The moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; those who are in the shadows of life, the sick, the needy, and the handicapped." I do not feel that I live in the shadows of life, but I do believe that the lives of people with disabilities are often relegated to the shadows of public consciousness. In times of stress or disaster, we are ignored. When resources or responses are designed, we are not consulted, but left to muddle through as best we can. Disabled people are often inundated with messages that tell us we are an unwanted burden on society, but during this pandemic, those messages have not been whispered, they have been shouted from the rooftops. Resisting these messages can be physically and psychologically exhausting, but we are worthy of protection. We have just as much right to live through this as our nondisabled brothers and sisters. Our society's failure to defend the elderly and disabled is a moral calamity that will haunt us for years to come.

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The ADA at 30: Not “Done” With Disability Rights

By Kelly Matula, PhD

Every so often, when able-bodied people hear that I do advocacy work for my fellow disabled people, they’ll say, “But the ADA was passed so long ago!” Very occasionally, they’ll add some version of the question that this statement seems to imply: “Aren’t we “done” with disability rights?”

The Americans with Disabilities Act, which is now nearly as old as I am, was of course immensely helpful. It required disabled people to be accommodated in public buildings and on public transit. It prevents us from being discriminated against in hiring decisions. It has paved the way for other laws protecting our rights to education and other essential services. I would undoubtedly not be where I am today without it.

However, the ADA is not a perfect or all-covering law. It mandates accessibility for new construction, but older buildings or smaller businesses can avoid having to be made accessible in various ways, as any wheelchair user who has tried to access a restaurant when all the entrances have steps surely knows. As someone who within the last several years had to find accessible housing in a new city, I am very aware that even though apartment buildings are required to have accessible apartments, that doesn’t mean they will have as many as disabled people who might need to use them. Filing a complaint under the ADA is also time-consuming and complicated, would require legal or other resources many people do not have access to, and might engender ill-will within the community. Having the protection of this law is great, but it doesn’t cover everything.

Even if the ADA did somehow result in everywhere suddenly becoming physically accessible, there is still the issue of ableism and anti-disability prejudice in society. A law can make overt discrimination illegal, but it can’t actually change people’s preconceived notions. And the articles in this issue have highlighted that able-bodied people still do have plenty of those, about the worth of disabled

people’s lives, how deserving they are of medical care, or whether they will make good parents. A law can’t automatically make people recognize and respect our dignity.

During the years when disabled people were fighting for legal protections like those they were ultimately granted in the ADA, the disability rights movement was sometimes called “the new Civil Rights Movement.” In the years since then, I have heard this term used to refer to other groups’ campaigns for fairer or more humane treatment as well, including in the fight for marriage equality and, more recently, other rights for transgender people. The phrase “the new Civil Rights Movement” often seems to imply that the “old” Civil Rights movement is over; Black people in America had their movement and how have all the rights they might need, so the name of “Civil Rights movement” can be passed on to another group. Sadly, however, this is not the case. The last few months have shown us all too clearly that, even though segregation and other forms of overt racial discrimination are now illegal, racism and racial prejudice are still very much alive in America, especially in policing and healthcare. They aren’t “done” fighting racism. No more are we disabled people “done” dealing with ableism and lack of accessibility in society.

The last several months have brought about a deep reckoning with racial injustice in America, and a reckoning that laws do not stamp out prejudice. I hope that the same recognition can come about disabilities, that people will recognize the ableism we still face in spite of legal protections and work to combat it and truly recognize our dignity. I hope that one day we will see a world when all lives--racial minorities, LGBT people, the disabled, the unborn, and others, will have their human dignity protected not just in legal rulings but in the hearts of every person in this country. The ADA and other laws like it have been huge steps on this path, but we still have a long way to go.