



# Life Matters Journal

V. 10, ISSUE 1 — FEBRUARY 2022

INSIDE THIS ISSUE:

## On (In)Quality of Life

Staving Off War: The Russia, Ukraine, and NATO Stand-Off

A "New Paradigm": The Stunning History of Human Rights Violations at Guantánamo Bay

Keep Ableism Out of Your Conversations About Prenatal Testing

# LETTER FROM THE EDITOR

Dear Reader,  
Happy New Year!

I am excited to get to share the first *LMJ* issue of 2022 with you.

As you may know, the beginning of the year is typically one of the most active months for those of us who work to educate and organize around issues of human rights and dignity. January alone holds several unfortunate anniversaries: the first execution in the United States' modern era, the opening of the Guantánamo Bay Military Prison in the context of the War on Terror, and of course the anniversary of the *Roe v. Wade* Supreme Court decision that legalized abortion throughout in this country. All of these events have resulted in horrific violence, discrimination, and dehumanization against our fellow human beings.

In the course of just two weeks this January, *LMJ* Editor in Chief Maria Oswald and I found ourselves organizing and participating in events related to each of these forms of violence.

In this issue, you will get the opportunity to learn about a range of topics relevant to human dignity. In A "New Paradigm," staff writer Samuel B. Parker looks back on the 20 years of Guantánamo Bay. In "Staving Off War," John Whitehead details the ongoing tensions at the Russian border and calls for diplomatic solutions rather than further Western escalation and aggression. We also have two disability justice advocates, Sophie Trist and Kristina Artuković, discussing societal ableism that leads to euthanasia, assisted suicide, filicide, and disability selective abortions.

Thank you for taking the time to read this magazine and educate yourself on these important topics. We hope that you will take what you learn and use it to create a more just world.

For peace and every human's life,

*Herb Geraghty*



# CONTENTS

**CURRENT EVENTS:** Staving Off War: The Russia, Ukraine, and NATO Stand-Off 1

**ESSAY:** A "New Paradigm": The Stunning History of Human Rights Violations at Guantánamo Bay 3

**ESSAY:** Keep Ableism Out of Your Conversations About Prenatal Testing 6

**ESSAY:** On (In)Quality of Life 7

# Life Matters Journal

FEBRUARY 2022

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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.*



# Staving Off War: The Russia, Ukraine, and NATO Stand-Off

By John Whitehead

**T**he long-simmering conflict between Ukraine and Russia now threatens to become open war. Russian military forces reportedly have been gathering close to the Russia-Ukraine border this fall. U.S. government sources recently suggested Russia might be preparing to attack Ukraine.<sup>1</sup>

War between Ukraine and Russia would be a devastating tragedy for both nations. Yet efforts by the United States and NATO to protect Ukraine could easily ratchet up east-west tensions further — and even provoke the war they are meant to prevent. Diplomacy to ease tensions and avoid armed conflict is urgently needed.

The current conflict arose in 2014 when an uprising in Ukraine overthrew the pro-Russian president. Russia responded by invading and occupying Ukraine's Crimea region. Also in 2014, armed separatists in eastern Ukraine began, with Russian support, a struggle against the central government. The civil war in Ukraine continues to this day.<sup>2</sup>

A 2015 ceasefire agreement required giving greater autonomy to the separatist regions while securing the central government's control, throughout the conflict zone, of the Ukraine-Russia border. However, this agreement has never been fully honored.<sup>3</sup> To date, over 14,000 people have been killed in the conflict.<sup>4</sup>

This fall, satellite photos and other analysis indicated that Russian troops and military equipment, including tanks, were moving closer to Ukraine.<sup>5</sup> Then came U.S. warnings of a possible Russian attack. Meanwhile, Ukraine has been massing its own troops, a move which Ukrainian authorities have justified as defensive but Russian authorities warn might signal a new campaign against the separatists.<sup>6</sup>

Whether Russia is actually preparing to invade Ukraine or is simply saber-rattling is ultimately known only to Russian President Vladimir Putin and his advisers. Understanding why Russia might be massing military forces close to Ukraine is easier to discern, though: the Russians have been very clear about their goals. Understanding these goals can help in understanding the current crisis and perhaps preventing war.

Russia wants to keep Ukraine from joining NATO — a path Ukraine has been contemplating since the 2000s. Putin raised the issue of Ukrainian NATO membership at a December meeting with Biden.<sup>7</sup> Later in December, Russian authorities proposed an agreement with NATO in which NATO would pledge never to offer Ukraine membership.<sup>8</sup>

Beyond NATO expansion, the Russians are generally concerned about western military activities close to them. As an official Russian statement commented, NATO “has been expanding its military potential near Russian borders.”<sup>9</sup> The recent Russian proposal includes a request for NATO to scale back significantly its military presence in countries close to Russia.<sup>10</sup>

Russian security concerns are understandable. Russia has no easily defensible western border: no mountains or seas separate Ukraine from Russia. Stopping an invasion from the west, through Ukraine, would be very difficult. If Ukraine joins an American-led western military alliance (NATO) and becomes a base for NATO military activities, Russia becomes extremely vulnerable to western attack. Russia has endured at least one such western attack every century for the past 400 years — the most recent, Nazi Germany's 1941 invasion of the Soviet Union, cost millions of lives.<sup>11</sup>

Modern military technology hasn't made the situation any more reassuring for Russia. In November, Putin expressed concern about NATO possibly stationing (presumably nuclear-capable) missiles in Ukraine. Such missiles could reach Moscow in 5 minutes. “The emergence of such threats represents a ‘red line’ for us,” Putin has said.<sup>12</sup> (Although stationing U.S. nuclear missiles in Ukraine is not an option currently being considered, the United States has given weapons and other military assistance to Ukraine.<sup>13</sup>)

Russian policymakers have a strong incentive to prevent further western military expansion into Ukraine. Preventing such expansion could involve supporting separatists, to weaken Ukraine.<sup>14</sup> It could involve invading Ukraine.

**This fall, satellite photos and other analysis indicated that Russian troops and military equipment, including tanks, were moving closer to Ukraine.**

However, the guarantee Russia wants — no NATO membership for Ukraine — isn't acceptable. While its concerns are understandable, Russia doesn't have the right to threaten another country into submission. Further, the United States and NATO are not going to agree to Russian demands: U.S. and NATO officials have repeatedly affirmed Ukraine's right to join NATO.<sup>15</sup>

Yet Ukrainian NATO membership remains very dangerous. At best, pursuing such membership will cause Russia to respond with its own assertive military activities, dramatically worsening tensions in Europe. At worst, the prospect of Ukrainian NATO membership will provoke a Russian invasion — precisely the opposite of the security Ukraine seeks from NATO.

The current stand-off doesn't have a clear solution. The best option for policymakers is some stop-gap agreement to buy time until (perhaps) better options become available. Such a possible diplomatic deal might include the following measures:

1. The United States, NATO, and Russia should seek a mutual reduction in western and Russian military activity in the region. The recent Russian suggestion of a ban on large-scale military exercises on either side of Russia's western border is worth pursuing.<sup>16</sup> This step would reduce the threat to Ukraine while also reassuring Russia.
2. The United States and NATO should slow the pace of any further military assistance to Ukraine and should defer consideration of Ukraine NATO membership for at least a few more years.
3. Ukraine and Russia should seek a new agreement on Ukraine's civil war — with an eye toward dropping the previous requirement that the central government gives autonomy to the separatist regions. Such talks offer Ukraine some political compensation for delayed NATO membership.
4. All the nations involved, as well as non-governmental groups, should provide appropriate humanitarian assistance to those in the conflict-affected region of Ukraine.

Whether such a diplomatic deal would succeed is uncertain. Even if successful, it would fall short of a satisfactory resolution. Nevertheless, a deal along these lines would be preferable to war or to the continual escalation of international tensions. Diplomacy should be seriously attempted.

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# A "New Paradigm": The Stunning History of Human Rights Violations at Guantánamo Bay

By Samuel B. Parker

**O**n January 11th, 2002, twenty inmates arrived at the Guantánamo Bay detention camp, becoming the first individuals to be incarcerated inside the notorious military installation. Twenty years later, almost 800 men have been confined at Guantánamo Bay, and at least 39 remain behind bars awaiting eventual prosecution or release.

"Gitmo" has long been the subject of intense political and ethical controversy both at home and abroad, and for good reason. The duplicitous tactics employed to install the facility as well as the treatment of the detainees inside have revealed the harrowing consequences of unrestrained state power and have shed light on the attitudes and actions of the darkest elements of the U.S. government. From its inception outside the boundaries of U.S. and international law, to demonstrable accounts of abuse and torture, to its present use as an extrajudicial holding site, Guantánamo Bay persists among the darkest stains in American history and is an ominous warning sign of what might follow.

## Background

Guantánamo Bay, situated on the south coast of Cuba, has been under U.S. jurisdiction since 1898, when the United States defeated Spain in the Spanish-American War. The Spanish empire had captured, colonized, and ruled Cuba since the late 15th century; however, following Spanish surrender to the United States at the end of the 19th century, the United States assumed control of and occupied the island for over three years.

In 1901, the United States agreed to withdraw from Cuba and recognize Cuban independence only under very specific conditions, ensuring that provisos that favored U.S. interests were codified into the new Constitution of Cuba. One of these stipulations was the Platt Amendment, which, among other things, delineated the details of a permanent contract that would ultimately grant Guantánamo Bay to the U.S. government, thus assuring the survival of the U.S. military base that had operated there since 1898.<sup>1</sup> Under the coercive threat of continued U.S. imperialist abuse and colonialist exploitation, the fledgling revolutionary government of Cuba was essentially forced to ratify the Platt Amendment, and thus to eventually cede territory to the United States under a lease that only the U.S. government was empowered to terminate.

In 1934, the U.S. and Cuban governments abrogated the Platt Amendment and repealed the provisions therein. The two parties mutually extended the lease for an indeterminate period of time and under renegotiated terms that specified that U.S. tenure of Guantánamo Bay could be canceled only if both the United States and Cuba consented to its annulment. But these changes were merely symbolic and had no practical impact on the nature of U.S.

presence in Guantánamo Bay. Although Cuba was ostensibly afforded equal influence over the lease agreement, the United States was still not required to abandon the region until and unless the U.S. government independently elected to do so. As a result, the Cuban government is still not capable of expelling a foreign power and exercising autonomous authority over its own lands.

The truly impotent nature of the Cuban state in these affairs became evident in 2015, when the U.S. government refused Cuban demands for the unconditional return of Guantánamo Bay.<sup>2,3</sup> To this day, the United States maintains a naval base in the area over the direct objections of the Cuban government and people: a protraction of the radical imperialism that has defined U.S. foreign policy for several centuries.

## Establishment of Guantánamo Bay Detention Camp

In the aftermath of the September 11th attacks and the subsequent launch of the War on Terror in 2001, the U.S. government faced a significant problem. A coalition that included U.S. forces was tearing across the nation of Afghanistan in an effort to topple the Taliban, which had assumed de facto control of Afghanistan in 1996 and had lent significant aid and protections to al Qaeda as the terrorist operatives plotted and coordinated the events of 9/11. As the Taliban retreated before a successful allied invasion, the U.S. military began taking captives, many of whom were suspected of participating in terrorist activities.

But U.S. government officials wanted to minimize the extent of activities in Afghanistan, and they realized that the construction of massive prison complexes would divert vital resources, human effort, and public attention from ongoing military operations. At the same time, they feared that interning captured Afghans in prisons located on U.S. soil would automatically confer the inmates legal rights under the U.S. Constitution.<sup>4</sup>

Their solution to this dilemma was Guantánamo Bay.

Because the terms of the U.S. lease ensure "complete jurisdiction" of the United States over Guantánamo Bay, the U.S. government would be able to transfer captives to Cuba without obtaining permission from the Cuban government. And, perhaps more sinister, because Guantánamo Bay is firmly controlled by the United States but does not lie within its national borders, advocates for the proposed detention camp argued that the privileges and immunities guaranteed by the U.S. Constitution did not apply to any captives held on the island.

As they weighed the various options for a new detention camp, officials in the administration of President George W. Bush admitted that one of their primary selection criteria was the external location of a site that would allow them to deny basic constitutional

rights and to evade U.S. court oversight and interference.<sup>5</sup> And in ensuing court battles, they referred to Guantánamo Bay as a “legal black hole”: one that they tried to fill with practically unlimited and utterly horrifying executive purview.<sup>6</sup>

But the Bush administration was not content to simply curtail the constitutional rights of prisoners at Guantánamo Bay. In a 2002 memorandum,<sup>7</sup> the White House advised certain members of the presidential cabinet and the Director of the C.I.A. that it intended to accept conclusions drawn by the Department of Justice that “none of the provisions of [the] Geneva [Conventions] apply to [the] conflict with al Qaeda in Afghanistan or elsewhere throughout the world” and that “[the president] ha[s] the legal authority under the Constitution to suspend [the] Geneva [Conventions] as between the United States and Afghanistan.” Specifically, the Bush administration insisted that “Common Article 3 of [the] Geneva [Conventions] does not apply to either al Qaeda or Taliban detainees” because detained members of al Qaeda and the Taliban “do not qualify as prisoners of war under... [the] Geneva [Conventions].” In a similar 2007 memorandum,<sup>8</sup> President Bush restated that “members of al Qaeda, the Taliban, and associated forces are unlawful enemy combatants who are not entitled to the protections that the Third Geneva Convention provides to prisoners of war,” without bothering to draw a concrete distinction between “unlawful enemy combatants” and “prisoners of war.”

The Geneva Conventions comprise four separate treaties and three protocols that collectively set an international legal standard for humanitarian conduct in wartime. They outline foundational rights and protections for war prisoners, wounded combatants, and noncombatant civilians. Common Article 3 of the Geneva Conventions concerns the humane treatment of captives; it explicitly forbids “violence to life and person [including]... mutilation, cruel treatment and torture” and “outrages upon personal dignity, in particular humiliating and degrading treatment,” and it dictates access to “judicial guarantees which are recognized as indispensable by civilized peoples.”<sup>9</sup> The U.S. government was searching for a way to preclude captives from taking advantage of these assurances, and they found it in Guantánamo Bay.

**The U.S. government was searching for a way to preclude captives from taking advantage of these assurances, and they found it in Guantánamo Bay.**

By incarcerating detainees outside of the United States, the Bush administration deliberately sought to deprive them of constitutional rights. By refusing to classify captives as prisoners of war, the Bush administration deliberately sought to deprive them of fundamental human rights. They did so with almost no hesitation and seemingly few compunctions.

Nor were these decisions made covertly. The White House publicly announced its intentions to purposefully skirt legal and moral accountability on both the national and international stage. They labeled this behavior a “new paradigm”: a fresh reality wherein they chose to engage in “new thinking [about] the law of war.” The chilling Orwellian undertones of these words are impossible to miss.

## Civil and Human Rights Violations at Guantánamo Bay Detention Camp

*(Warning: torture and violence)*

Detention at Guantánamo Bay began on January 11th, 2002 with the arrival of 20 captives from Afghanistan. In the intervening decades, the site has witnessed some of the most appalling events of the modern age. Incriminating testimony from workers and verifiable prisoner accounts alike recount contravention of legal rights, gross negligence, and torture. In spite of the fact that U.S. court rulings in 2004 and 2006 summarily rejected claims by the Bush administration that Guantánamo Bay fell outside of U.S. judicial jurisdiction and beyond the scope of the Geneva Conventions, the “legal black hole” has enabled the U.S. government to indefinitely detain and repeatedly maltreat inmates.<sup>10,11</sup>

Amendment VI of the U.S. Constitution<sup>12</sup> expands upon the concept of “due process” found in Amendment V before it,<sup>13</sup> enumerating the components of the indispensable right; together, the amendments indicate that “no person shall be... deprived of life, liberty, or property without... a speedy and public trial [emph. added]” and without being informed of “the nature and cause of the accusation” leveled against them. Essentially, the right to due process proscribes the detention of individuals for unreasonable durations and requires that detainees are made aware of the charges against them. While the term “speedy trial” is contextually ambiguous, the Speedy Trial Act of 1974 that “defin[ed] the Sixth Amendment right” mandated that “the period of delay in all federal and district courts shall not exceed 100 days,” with exceptions authorized by trial judges for special or extenuating circumstances.<sup>14</sup>

Moreover, Article I, Section 9, Clause 2 of the U.S. Constitution and several federal statutes enshrine the writ of habeas corpus in U.S. law.<sup>15</sup> Latin for “that you have the body,” the “Great Writ” of habeas corpus is a common law recourse that entitles prisoners to dispute the legality of their pretrial detention on several grounds, such as an absence of formal criminal charges.

In sum, the prolonged and indefinite custody of uncharged detainees qualifies as unlawful imprisonment according to U.S. law. And yet, many of the inmates at Guantánamo Bay have languished for years, some since 2002, without being formally charged with a crime, undergoing a jury trial, or otherwise enjoying their right to due process.<sup>16</sup> Surely, twenty years—more than a third of the average human lifespan—is anything but “speedy.” And while the prisoners at Guantánamo Bay have the technical right to challenge their detention under the writ of habeas corpus, the U.S. judiciary has abdicated its responsibility to check and balance its executive counterpart: lower courts have denied such attempts due only to the former associations and personal contacts of detainees, and the U.S. Supreme Court has routinely declined to rule on appeals.<sup>17,18</sup> Through both calculated executive action and judicial acquiescence, the U.S. federal government has meticulously designed an indefinite detention program and, in the process, has orchestrated a systemic infringement of the civil rights that supposedly lie at the heart of the United States.

Simultaneously, reports of barbaric torture have emerged from Guantánamo Bay. In 2002, the Bush administration approved the use of “enhanced interrogation techniques” against “high value” inmates at Guantánamo Bay.<sup>19</sup> The most infamous example of

these techniques was waterboarding, a tactic in which “the detainee is immobilized on his back and water is poured over a cloth on his face” in order to simulate asphyxiation by drowning; waterboarding causes severe brain damage, critical lung distress, loss of consciousness, and bleeding from facial orifices. The C.I.A. also implemented lesser known “enhanced interrogation techniques.” Some detainees were “walled,” a tactic in which their heads were “encircled with a collar,... and then slamm[ed] against a wall.” Others were shackled in stress positions (upside down, arms over heads, confined in boxes, etc.), forced to stand on broken feet, anal-ly penetrated for medically unnecessary rectal feeding, exposed to extreme temperatures while naked, shaken violently, repeatedly struck in the face, and subjected to sensory and sleep deprivation.

The euphemism “enhanced interrogation” allowed U.S. officials to plead ignorance and innocence when accused of committing war crimes by resorting to torture. But the law, both domestic and international, is clear. In the United States, 18 U.S.C. 2340A criminalizes “acts specifically intended to inflict severe physical or mental pain or suffering.”<sup>20</sup> Globally, the U.N. Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment prohibits “any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person.”<sup>21</sup> Correspondingly, Article 16 of the U.N. convention instructs all members of the international body to “undertake to prevent in any territory under its jurisdiction other acts of cruel, inhuman or degrading treatment or punishment,” even those that do “not amount to torture.”

The U.S. government was eventually confronted regarding its use of “enhanced interrogation techniques.” The defense? A play-list of the old favorites. “Enhanced interrogation techniques,” they asserted, did not breach U.S. law because, while “certain acts may be cruel, inhuman, and degrading, [they] still [do] not produce pain and suffering of [a] requisite intensity... that is difficult to endure[,]... such as organ failure, impairment of bodily function, or even death,... to fall within Section 2340A.”<sup>22</sup> In other words, officials in the Bush administration contended that, by the arbitrary estimation of the perpetrators (and not the victims), “the infliction of pain” was “insufficient[ly]... severe... to amount to torture” under U.S. law. Meanwhile, they stated that “enhanced interrogation techniques” did not transgress international law because U.S. obligations to Article 16 of the U.N. convention are “limited to conduct within ‘territory under [United States] jurisdiction,’... [and enhanced] interrogations do not take place in any such areas.”<sup>23</sup> As many had predicted and feared, the U.S. government pointed to the foreign soil of Guantánamo Bay in order to justify and excuse obvious war crimes.

## Guantánamo Bay Today

Currently, 39 of the original 780 detainees remain at the Guantánamo Bay detention camp. Two of the last three presidents have vowed to close the facility and end one of the worst chapters in U.S. history. So far, neither has fulfilled that promise.

“Enhanced interrogation techniques” were discontinued in 2009, when President Barack Obama signed an executive order that expressly eliminated government torture.<sup>24</sup> And while detainees at Guantánamo Bay are allegedly spared physical violence at the hands of their captors, their legal standing remains the same:

stranded in a no man’s land intentionally crafted to prevent them from any and all means of escape.

The Guantánamo Bay detention camp has become an integral part of the national legacy, and will be inextricably linked to U.S. history at the turn of the century. It is unfortunately impossible to reverse this grave error and undo the damage that has been rendered upon the reputation, credibility, and moral integrity of the United States.

But it is not too late to close the Guantánamo Bay detention camp, offer restitution to its many casualties, enact laws that will comprehensively impede the recurrence of such deeply wicked transgressions, and restore Cuban lands to the people of Cuba. If Americans do not expect and demand leadership that is committed to these objectives, they will concede to total compromise of supposedly American ideals.

The “new paradigm” must not continue. Otherwise, the paradigm that inevitably comes next will surely dismantle what remains of civil and human rights in the United States.

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# Keep Ableism Out of Your Conversations about Prenatal Testing

By Sophie Trist

The *New York Times* rang in the new year by releasing its findings that many popular prenatal genetic tests are inaccurate as much as 85% of the time.<sup>1</sup> Tests for common conditions like Down syndrome are very accurate, but when it comes to rarer disorders, a positive result is nearly always false. For every 15 times the tests correctly identify an anomaly, they are wrong between 80–85 times. These findings have profound implications for our conversations about pregnancy and disability-selective abortion. The conversation around prenatal testing is usually rife with ableist assumptions and stereotypes, and this *New York Times* article is no different.

It begins by telling the story of Yael Geller, who finally became pregnant after a year of fertility treatment only to learn that her baby was missing a piece of one chromosome, what geneticists call a microdeletion.

“Sitting on the couch that evening with her husband, she cried as she explained they might be facing a decision on terminating the pregnancy... The next day, doctors used a long, painful needle to retrieve a small piece of her placenta. It was tested and showed the initial result was wrong. She now has a 6-month-old, Emmanuel, who shows no signs of the condition he screened positive for.”<sup>1</sup>

If the initial test had been accurate, the parents likely would have had an abortion, and the subtext of this article insinuates that they would have been right to do so. This is far from the first story to push the narrative that prenatal testing is problematic because an inaccurate result might lead to a “normal” baby being killed.

In 2014, NBC News ran an article about how the competitive prenatal testing industry is deceiving customers about the accuracy of its noninvasive tests.<sup>2</sup> The first sentence of the article rings with ableist overtones. “Zachary Diamond and Angie Nunes look at their ‘wonderfully healthy’ 6-month-old son Solomon, knowing they might have terminated the pregnancy — all because of a popular prenatal test that was wrong.” The article tells a similar story about a Rhode Island woman named Stacie Chapman, whose unborn son was misdiagnosed with Trisomy 18, after which she immediately scheduled an abortion that she didn’t go through with because her doctor urged further testing. She describes the rest of her pregnancy as traumatic and says that she didn’t want to bond with the baby. Amniocentesis revealed that Stacie was probably carrying a “normal” child. When her son Lincoln Samuel was born without any disabilities, Chapman described him as perfect.

He would have been perfect even if he had been born with Trisomy 18.

In 2018, South African journalist Claire Bell received a fetal misdiagnosis of Turner Syndrome. According to the BBC, the information on Turner Syndrome that Ms. Bell received from the clinic painted a very grim picture of life with the condition.<sup>3</sup> She thought that this was science, indisputable facts, and aborting her daughter would be the kindest thing to do. As with Yael Geller, Stacie Chapman, and the rest, further testing revealed that Claire Bell’s baby was “normal,” and she was born perfectly healthy.

All of these stories about inaccurate prenatal testing have fairytale endings in which “normal” babies are saved from abortion by further testing. I have even seen this well-meaning but extremely ableist trope play out in a few testimonies from pro-life organizations.

It is tragic that hundreds of unborn children have doubtless been killed because of these false positives, but children who actually have rare disabilities are just as valuable and just as worthy of life as those who were misdiagnosed. The humanity of disabled babies is nowhere to be found in any of these narratives. None of these stories challenge the assumption that if the test result had been a true positive, abortion would have been the compassionate and correct choice. Disability remains the Boogeyman under the bed, the disaster averted. “It almost happened to us!” these narratives cry. “But Thank God further testing revealed that my baby was normal and thus worthy of existing.”

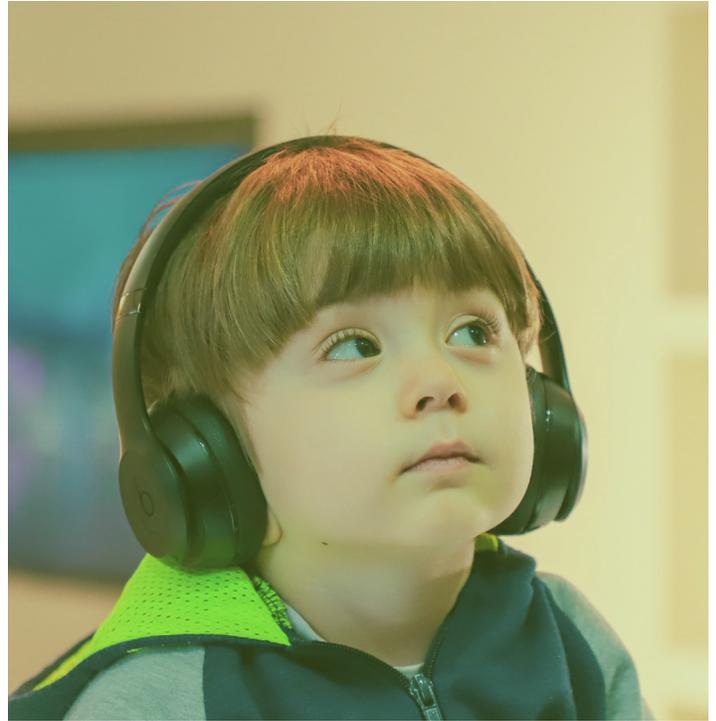
Amy Julia Becker, the mother of a daughter with Down syndrome, offers a moving reflection on the problematic, eugenic nature of our narratives about prenatal testing.

“In retrospect I wonder why I spent so much time convincing myself that the test results would be negative. I spent no time thinking about why the prospect of a child with Down syndrome caused such tightness in my chest, such a need to convince myself that it couldn’t be true of my child or within my family. Why was I so frightened of Down syndrome? Was it the way the tests were presented, the aura of somber intensity that came along with the uncertain results? Was it fear on behalf of my baby? Or fear for myself? Did it disrupt a hazy vision of the life I had always expected our family to lead? Was it the fact that a diagnosis of Down syndrome automatically led to a conversation about abortion, that Down syndrome automatically led to a choice that wouldn’t have otherwise been on the table? I didn’t ask myself any of those questions back then. I just wanted a healthy baby.”<sup>4</sup>

These recent findings by the *New York Times* validate disabled people's fears that prenatal testing is often used as a weapon to eliminate us before we're even born. But most of the coverage on the unreliability of these tests focuses on the "normal" babies who were saved, not the inherent dignity of the disabled babies, whose lives are still seen as less valuable. Prenatal testing is not intrinsically evil. It can be used to help new parents prepare for life with a disabled child, because that life will not always be an easy one. But prenatal tests should never, ever determine which babies live and which babies die, not only because they're often wrong, but because all children, regardless of disability, are people with incalculable worth and human dignity.

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ESSAY

# On (In)Quality of Life

By Kristina Artuković

People with a health condition, chronic illness or disability — even people like me, who have a child with a disability — are all too well acquainted with the concept of quality of life. These three words pop up constantly: in doctors' offices, in literature on particular health issues, in everyday conversations. Like electrons around the core, they buzz around our intimate dealings with dependency, forming a tacit system that governs the way we conceptualize the fragility of our existence. However, the concept seems quite elusive: it appears both as a noble goal and an insidious criterion in medical practice; it serves as an all-purpose term for how well individual people are doing, and also as a means of rating how a society is functioning. What exactly is quality of life?

## History: 50 shades of progress

The concept rose to prominence in the 1960s when post-WW2 society's love affair with material progress began to profess some dystopian streaks. Social scientists and interested parties from the technocratic realm aimed to formulate a response to the sharply protruding disparities between technological and economic advances on the one hand, and various social issues on the other.

There were many areas of concern. Alienation, civil unrest, cults, crime rates, drug abuse. Just like in today's imaginarium of impending doom, overpopulation and pollution were prominent among the mainstream's hot topics. Quality of life was thus a response to the disillusionment of pseudo-affluent society, formulated as a truer aim for socioeconomic development, often reduced to *happiness* stemming from financial and social stability, health-related wellbeing, education, cleanliness, resources, etc.

From there on, the concept split into two streaks: one gave rise to various measurements of social indicators to be piled on the desks of benevolent technocrats, while the other gradually assumed the form of a medical decision-making tool known as health-related quality of life (HRQoL).

Today, the first streak is present in numerous forms of general population measurements. For instance, those provided by OECD, World Health Organization, and the European Union all assess factors like education, wealth, physical safety, natural and living environment, etc.

In the "first, do no harm" realm, the concept started gaining momentum in the 1970s. Some authors bluntly advocated for

abortion and sterilization towards improving the overall quality of life, while others shared their concerns about low-income families birthing children with disabilities and other “dysfunctions.” The lives of people with Down syndrome, spina bifida, dementia, diabetes, and mental health issues were unblinkingly framed as “failures of success.” The fact that technological breakthroughs in medicine apparently resulted in an uncontrolled number of people whose lives depended on healthcare troubled many.

Medical practice entails hard decisions, especially when it comes to the issue of prolonging patients’ dying. The dilemma of whether to proceed with aggressive and painful treatments or commence palliative care instead has been around at least since the Medical Renaissance. The Catholic Church articulated a sophisticated doctrine of ordinary and extraordinary means of care, the latter referring to treatments that imply “physical or moral impossibility” for the patient. The proponents of health-related quality of life sometimes brushed against these issues when spreading out their rationale. However, the concept of quality wormed its way into the broader practice by simultaneously appealing to empathy and implying a tolerance threshold for biomedical abnormality. So it quickly became a general framework for tackling the *purpose* of a medically supported *life*, which is very different from the *purpose* of clinically prolonged *dying*.

### Practice: scores that score you out

Not long after the rise of health-related quality of life, the construct became formulated as an explicit numerical devaluation of a care-requiring life, packed and sold as “quality-adjusted life years,” abbreviated as QALY.

Today, QALY serves as a decision-making tool for the allocation of health-related resources. This bizarre apparatus bends the time-space continuum to shrink a life year of people who require care in order to survive. It’s very intuitive: if a technology (medication, treatment, devices) is predicted to give you one additional year of life at total wellness, your life is then one quality-adjusted life year long. But all 365 days of your year may not amount to one quality-adjusted year if your wellness during this period has not been absolute. In that case, your year is not a healthy person’s year – it gets amputated into a decimal between 0 (dead person) and 1 (absolutely healthy and utterly happy person). As the year gets shorter (for instance, your year might be 0.36 of an ideal person’s year), the less chance there will be for a specific health technology to enter into general practice.

QALY numbers are first generated via patients’ confessions collected through various questionnaires, combined with monitoring in clinical trials, and are then grouped into databases published for the decision-makers’ use. From there, QALY numbers enter a formula of cost-effectiveness for a particular health technology, and the result is compared against a financial threshold of tolerable costs. This threshold is set arbitrarily, in regard to the country’s health budget, its social policies and socioeconomic politics, etc.

Generally, health-related quality of life, along with the tools that yield its scores, has often been promoted as giving the patients their voice. But this voice is heavily pre-articulated, containing a clearance of the social bias account. There are many measurements and models. For example, the SF-36 questionnaire and the Health Status Index (HSI) produce scores depending on how people func-

tion, feel, socialize, move, etc. They all contain an implicit assumption that a limited scope of activities necessarily lowers the quality of life. In addition, the unassessed but pre-existing state of the environment – lack of resources, lack of accessibility, lack of available treatment, lack of acceptance, lack of support, pervasive ableism and ageism, including internalized discrimination – constitutes an enormous but normalized slice in the pie chart of the reasons why people might score lower, and the scores largely differ in relation to these factors.

From the standpoint of disability, people’s own voices are used as amplifiers of bias and stigma; this doubly predetermined lowering of scores demonstrably diminishes the chance of people receiving bias-free or affordable care — which means that this tool makes a bad environment even worse. Ultimately, with many iterations of the formula that contains the implicit constants of unaddressed biases and obstacles, the entire process can only result in a limited access to life-saving care and a disregard for accessibility.

On top of all of this, there also exists a blatant disregard of the opinions of people with disabilities that do not fit the narrative. For example, 99% of people with Down syndrome state that they are happy with their lives, and yet doctors push for their termination in the name of quality of life. This leads to a common trauma among the parents of children with Down syndrome – common, but far from being justly documented in the research papers arena. Disability advocates have a long record of pointing out their satisfaction even in the face of pain and discomfort, and despite tremendous social obstacles, with little or no impact on quality of life calculations.

For example, 99% of people with Down syndrome state that they are happy with their lives, and yet doctors push for their termination in the name of quality of life.

All these issues demonstrate that the QALY apparatus results in an almost non-negotiable standardization of the medical model of disability, enshrining it within the decision-making processes from top to bottom, totally putting out of action the social model of disability that minds the intricate way in which the society constructs and governs the concepts of disability that hover over people’s impairments.

It is undeniable that some kind of rationale will always be required when it comes to distributing health-related resources, but why not focus on quality of *care* rather than on “quality of life”? From the very beginning, the quality of life construct has been deployed to shift the system’s responsibility for providing quality care onto care-requiring people themselves, according to their biomedical “quality.” The utility of intervention or treatment will remain a factor, but less discriminatory tools for addressing it have already been proposed.



## Ideological foreground and background: utilitarianism and biopower

Today, there is an entire array of lethal medical practices associated with quality of life, revealing it as a loose cannon of systemic bias: pressure to abort children with disabilities, denying medical care to congenitally affected infants, denying organ transplantation to disabled babies, neonatal euthanasia, giving unconsented do-not-resuscitate orders, denying medical care to disabled people, unconsented euthanasia.

Ever since quality of life gained traction in the medical sphere, it has been enmeshed with the tropes of “needless suffering” and “maximization of quality.” Both of these concur with the core principles of utilitarianism, a moral doctrine bent on achieving the greatest happiness for the greatest number of people. Happiness is defined as pleasure or lack of suffering.

So the pursuit of utilitarian aggregate happiness via hedonic calculus finds its medical counterpart in the production of aggregate biomedical quality via assessment tools, both revolving around the “minimization of suffering.” However, in these epistemologically limited frameworks, suffering has seldom been analyzed minding how human beings relate to, reflect on and process suffering. Both are marked by substantial disregard of everything we know or intuit about human ability to find meaning and joy despite or precisely because of our suffering. Moreover, when it comes to unavoidable or pre-given circumstances such as imperfect health or impairment, deeper analysis reveals one of the most distinct blind spots of these approaches: human beings often get equated with suffering, and their existence with moral wrong. Meaning: humans are constituted as subjects of quality through reduction of the sufferers to suffering objects. This objectification is precisely why medical rendering of utilitarianism results in such lethality, from prenatal eradication to systemic discrimination in other stages of life.

Both frameworks are also epistemologically incapacitated to address the issue of how suffering assumes its semantics through various vectors of power that govern the processes of forming the expectations from our bodies and minds. In other words, how we construct disability and create notions of suffering through bias, stigma, ableism and ageism. It’s ironic, almost to the point of travesty, that utilitarian pop-stars (for instance, Richard Dawkins, and the slightly more sophisticated, but equally careless Peter Singer) have caused palpable suffering throughout the disability community.

What is the ultimate purpose? It is not to control the costs of medically defined quality – that’s just part of the mechanics. It is not to maximize happiness or minimize suffering – that’s just a smoke screen. In these calculus, the ultimate bearer of happiness/quality is no one, anyone and everyone: social order itself. This insight empowers us to see these frameworks for what they are, and for that, I’ll have to borrow some more from Foucault: these are modes of biopower. This is power over people’s lives and bodies: it either shapes, upholds and invests in life, or disinvests in it to the point of death, according to the criterion of systemic suitability. Individuals are not simply subjected to biopower, they also produce and channel it. This is not some empty theorizing, it’s very concrete. Parents who terminate pregnancies because of disability, persons who request assisted suicide, people who slap do-not-resuscitate orders on the beds of cognitively impaired persons, people who assess others to see if the quality of their life is sufficiently poor for euthanasia, random people who offer pity on disability, philosophers who make up criteria of intraspecies moral statuses, and so on.

Pleading for equality will not do against the workings of biopower; it subverts the relevance of equality in at least two ways: by dispersion of lethality to individual decisions, and by creation of sub-groups that possess different moral statuses. Pointing out the original ethics of medicine will not do – as we speak, it is being rewritten to adjust with the times. Laws are already being bent to the production of “vital population” by processes of absolute exclusion at both poles of human life.

However, of this I am certain: the path to liberation begins by dissolving the notion of the functional uniformity of humankind. Yes, we have relevant *abstract* traits, but we all embody them to various degrees, while our *mutual dependency* actualized in the culture of justice allows for a widest possible range of individual modes of functioning. The imaginary line between biomedical normality and abnormality has to be erased if we are ever to achieve a culture that provides *radical acceptance* instead of *controlled inclusion*. This path will be paved by honoring “*not self-sufficiency but self-determination, not independence but interdependence, not functional separateness but personal connection, not physical autonomy but human community*,” as Longmore brilliantly put it. Then we will be ready to handle someone else’s mode of existence instead of evaluating the quality of other people’s lives.

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