# The Body She Had

***If only parents could be spared the terrible freedom of being forced to choose . . .***

ROSEMARIE GARLAND-THOMSON

"My husband and I decided that it was a loving decision not to bring her into the world with the body that she had."

This line from a recent newspaper article on abortion rights stays with me when I'm quiet in the early morning before my day of obligations and pleasures begins. This girl who is not in the world because of "the body that she had" had a body like mine and a body like those of many of my friends. She was a girl with a body we now talk about as having a significant congenital disability. The piece referred to her as a "pregnancy," rather than the girl whose memory haunts me. Parents like hers, writes the journalist, "speak of the pregnancies they lost as unborn children." Her parents carried out what they believed to be their obligation to her by saving her from what they imagined was a life diminished by suffering and debility, a life not worth living.



Tim Lowly, *Parel*, acrylic on panel, 2014.

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Over the decades of my long life, I have collected a strong and secure group of friends, mostly women. We are educators and writers, and we have bodies also understood as having significant congenital disabilities. Several of us are blind or partially blind; a few use wheelchairs; some are Deaf; there's some neurodiversity and a good amount of physical asymmetry. We all managed to get a good enough education to develop our capacities to talk, think, and write, often in unusual and unexpected ways. Most of our schools tolerated more than welcomed us, but felicitous temperaments and at least good-enough mothering gave us the building blocks of the good lives we all now inhabit. Like most everyone else with a life of flourishing and joy, we have lives shaped by a balance of good fortune and grit.

The difference between this girl who is not in the world and my friends and me who are in the world is that before we were born into the world, our parents did not know what kind of bodies we would have. We were born, for the most part, before the profiles, information, and images of the prenatal testing era sketched out our being and future for waiting parents. Now the bodies we have are named as medical conditions: syndromes, rare diseases, skeletal dysplasias, genetic anomalies, and more pathologies. These descriptions of our bodies pin us to the world like specimens in museums. Yet in truth we are the flesh and bone and blood that have lived our lives, done our work, thought our thoughts. With these bodies, we have loved and been loved by many others along our way.

When we appeared in the world, our parents were unsettled, even shocked. We simply showed up without a story. They had to take us in, and they did, even though certain aspects were unexpected and unwanted. They did not choose us: they held us in their arms because they had to. Some of us were indeed given away or locked away, but most of our parents held on to us despite their bewilderment. We were gifts that stretched our families' humanity, but no one much recognized that at the start. We made lives for ourselves from our circumstances and our temperaments, as do all our fellow humans, living as freely as we could within the constraints of our place and time, our embeddedness in the world.

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This girl with a body like ours who is not in the world might have had a life like ours. Her parents must not have known that when they made the "loving decision not to bring her into the world with the body that she had." I am unsettled by their decision, wanting them to know us, wanting to say to them that she would have been all right. Experiences much like the human variations and frailties we think of as disabilities come to all of us eventually. The girl who is not in the world and her parents might have learned this if she had joined us in this world.

The parents of that girl with a body like ours bear a terrible freedom. This freedom that modern liberal societies offer has often become a heavy mantle thrown over the shoulders of parents as they exercise their right – this onerous obligation – to choose who they bring into the world. The authority of a medical diagnosis and the life it predicts can overwhelm other possible stories of shared lives well lived.

While the intention of medicine and health care is making people as normal and healthy as possible, the outcomes of medical practice

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often eliminate people disqualified from those categories. The parents of our lost girl had to imagine her and the woman she would become; they had to judge her future life before they had the chance to meet her. The choice they had is perhaps the most significant moral choice freedom presents because it determines who can and cannot enter our human community. This imagining, judging, and choosing are obligations that medicine has put before parents but for which they have almost no meaningful guidance.

This freedom to choose who enters the family and our shared community is constricted by the limited stories available to parents about possibilities for human flourishing. Most people do not know the stories of livable lives for girls who come into the world with bodies like mine and my friends'. Abandoned in the reproductive clinic, the parents of these lost children lack these stories. They must choose whether to "terminate the pregnancy," a moral action expressed in language that distances them from their daughter, already inhabiting her own tiny, hidden body, intent on coming into the world to join their family.

The parents of the girl with a body like ours who is not in the world were perhaps not offered much information beyond the medical context of their daughter's predicted health condition. They may not have known about the duties of government and community to care for and sustain their daughter and their family. The rigorous commitment to the freedom of self-determination and individual autonomy, as philosophers such as Alasdair MacIntyre point out, perhaps eclipsed a more communitarian moral obligation to welcome, embrace, and care for one another.

Decisions about what kinds of people to bring into our families and the world grow heavier as the array of reproductive medical technologies expands. We find ourselves with new options available: Should I have this screening? Should I use in vitro fertilization? How should I select embryos? What am I to make of a polygenic risk score? Utilitarian philosopher Peter Singer calls this "shopping at the genetic supermarket." All these freedoms, all these choices, and all this information is somehow in the interest of keeping people with bodies like mine and my friends' and the girl who is not in the world from joining our families and communities.

Until recently, parents could only begin intentionally shaping the being and lives of their children after they held their newborn child in their arms. The new human being, separated now from the body of her mother, insisted with her visible presence that she be recognized as a distinct person with a recognizable will of her own and a full moral and legal status. For the most part, laws, professional protocols, standards of practice, and communal traditions initiated at birth guide parents' choices and consent. Unsettled as any parent might be by a baby who is not what they expected, that baby enters into the world surrounded and supported by an array of people – lactation consultants, nurses, obstetricians, midwives, neonatologists, pediatricians, surgeons, grandparents, relatives, clergy, family friends – all of whom welcome the newborn to her community. People come bearing gifts: pink and blue hats, onesies, blankets; if necessary, intubation, medication, incubators, medical skill, spiritual guidance, and moral sweat. Her status as a newborn human protects this most vulnerable of beings. Parents stunned by the revelation of a baby who is different from what they expected or wanted are nonetheless invited to make the best of what they got.

This girl, placed in her mother's arms, squirming and squalling and demanding attention and care, has little relationship to the risk profiles, diagnoses, prognoses, prenatal testing, or leaflets that shape her parents' decision-making. These obscure the enfleshed person who is their daughter, hidden from them deeply in the womb. With only this pathological picture, her parents do not yet know her in the human ways that we know and recognize one another. An increasingly

Tim Lowly, *At 25* (front and reverse),
acrylic, gold leaf, foil, gold pigment, and glitter on wood, 2010

**About the artist:** Tim Lowly is a Chicago-based artist, curator, musician, and teacher. His daughter, Temma, who has cerebral palsy with spastic quadriplegia, is a central subject of his work. Below, he explains the paintings in this piece.

***Parel*** (page 64): "In Vermeer's iconic painting *Meisje met de parel* (Girl with a Pearl Earring) the pearl could be understood as suggesting the young woman possesses a beauty as 'pure' as a pearl. That said, it seems possible that in the context of seventeenth-century Netherlands, the painting might have been perceived as being about desirability. This understanding of the painting might be corroborated by the girl's gaze. By contrast, in this painting, Temma does not engage the viewer. At one point when my wife Sherrie was looking at the painting she said, 'It looks like a pearl.' She might have been referring to the surface of the paint, but I think there's a way that the painting points to the mysterious translucence and opacity of Temma's presence as something like – and, curiously, as beautiful as – a pearl."

***"At 25*** [above] was made as a kind of commemoration of twenty-five years of working with my daughter Temma as a subject and a collaborator in my art. The piece is composed of twenty-five sections, each of which is painted by one or two artists from around the world. For the front of the image I provided the participants with a section of a portrait photograph corresponding to the piece they were given. I also gave them black and white matte acrylic (the paint I usually use) and asked them to render the photograph as stylistically neutrally as possible. For an artist to set aside their style is a significant gesture, and as such I am very grateful for how willingly and sincerely the participants took on this part of the project. For the back side of the work the directive was much more open: 'Make it gold.' As anticipated, the result was that the back looked very eclectic, like a friendship quilt."

burdensome clinical view overtakes their understanding of her, blunting their imaginations.

Before they hold her in their arms, this clinical picture of their daughter supplants the experience of holding and beholding her that begins the relationship of mutual recognition between parents and their child. Such face-to-face encounters between humans, philosopher Emmanuel Levinas tells us, ground our moral relations and establish our bonds of recognition and solidarity. Only through this direct embodied encounter does the kind of human solidarity that binds families and communities together take hold. Although a mother begins to know her child during gestation, the face-to-face bond that holding and beholding her baby forges is less vulnerable to the interrupting abstraction of a diagnosis. We are most capable of loving particular human beings, distinct persons whose tender faces and fragile bodies we directly encounter.

To love is the act of recognizing one another, of witnessing the uniqueness of distinct human beings, precious and irreplaceable. The denial of a face-to-face encounter with her parents reduced that girl to one pathologized characteristic. The clinical image of that girl with the body like mine and my friends' overtook her whole being, blunting the generosity recognition brings. The static fact of her diagnosis overwhelmed other versions of how she might have lived, who she might have been, and how we might all have loved her.

The girl who is not in the world had the same potential for living a good life as any of us. Although some disabled people must live in an unwelcoming social and built environment, our disabled bodies and minds do not necessarily determine our quality of life or our prospects. What determines human flourishing is not whether a person lives with a disability but whether she is sustained by an environment of fellow humans and their offerings of resources and care. We all need to live in an environment that supports the needs of our bodies, minds, and souls. That girl with a body like mine might have lived with dignity, surrounded by strong relationships, sustained by an accessible environment, supported by adequate economic resources, and embraced by a just and accommodating community.

How can we reimagine the life lived by this girl who is no longer in the world? How can we understand the terrible freedom her parents acted on, believing it would spare her suffering? How can we challenge the quality-of-life statistics that her medical diagnosis and other utilitarian calculations predicted? On what grounds can we offer a different "loving decision" that would welcome her among us? How can loving her differently than they did come to be a tenable, freely chosen option for her loving parents?

To make a different "loving decision" in support of their daughter's existence and her right to an open future, her parents might have turned to a literature of welcome, largely absent in the closed environment of the clinic. The modern dilemma of spiritual isolation from one another – and perhaps from the divine – has been taken up by a range of thinkers whose writings might have enabled the parents of the girl who is not in the world to reimagine their daughter, her life, and how they might have loved her in a different way. These writings clarify concepts and practices such as dignity, attention, recognition, distinctiveness, justice, equality, community, and love. They speak of universal and equal human dignity by extending the Christian tradition of *imago Dei,* being made in the image of God – a reverence for life that welcomes people with bodies like ours and hers.

This literature of welcome stretches far back in the shared wisdom traditions of our world. In modern times, philosopher Hannah Arendt reawakened an attitude of welcome at a time of great human reckoning. As a witness to the Holocaust and a victim of its hatred, Arendt repudiates the injustices that the toxic merger of eugenic ideology and totalitarianism brought to the world.

"Political regimes ought not to determine who should and who should not inhabit the world," she proclaimed in her 1963 report on the trial of Adolf Eichmann. Arendt recognizes that the eugenic regimes of the twentieth century foreclosed on human diversity and potentiality. She defies moral hierarchies based on both ancient tribalism and modern medical science. Covenants such as the Universal Declaration of Human Rights and the various equality movements, laws, and practices that sought to strengthen human justice responded to these violent moral affronts similarly. They were nascent welcoming gestures of a chastened human community, one that insisted we must, under all circumstances, recognize each other in equal dignity, despite how alien we may seem to one another.

In the wake of the Holocaust, Arendt argued that our human condition centers not on the shared mortality that we have so relentlessly imposed on one another in her century and across human history, but in our shared natality, the solidarity we might forge by recognizing that we all share birth before we share death. For Arendt, the call to human solidarity that our shared natality prompts is *Amo: volo ut sis:* "I love you: I want you to be." It appears in her posthumously published lecture "Willing." Like Levinas in his call to recognize the face of the person in front of us, Arendt proposes an ethics of nearness, inviting others into the human community and charging us to offer inclusion to all people, bound by the shared experience of being born. An attitude of welcoming attentiveness rather than ownership is the proper relation between members of the human community, particularly between parents and children. The welcoming call of natality recognizes that the solidarity amid diversity that constitutes unequivocal equality is the premise of membership in our human community. With this desire for others to be, Arendt offers the freedom to choose stewardship over selection as a model of parental love.

Arendt's natality welcomes the child at the moment of birth. Levinas's beholding assumes another whose face is already visible. The face of the girl with the body like ours was hidden from her parents at the time they made their "loving decision" to spare her from what they imagined as a life of suffering. Their reproductive decision-making circumstance denied them the chance to behold her face, hold her in their arms, and know her in her distinctive, fully human form. In the array of information presented to this girl's parents, was a meaningful vision of her as a beloved, distinctive, embodied person offered? Their loving decision cost them both their daughter and their chance to offer her the friendship we might all extend to one another as a welcome into the world.

**In the array of information presented to this girl's parents, was a meaningful vision of her as a beloved, distinctive, embodied person offered?**

Where for those parents was a group of women like my friends: women with bodies like their daughter's, who befriend each other and who live good lives? The girl's parents were abandoned in their terrible freedom to choose whether to bring their daughter into the world with the body she had, to grow as she might – and for them to recognize her as theirs. What keeps me awake at night is wondering how my friends and I might accompany such abandoned parents, how we can help them behold her in a different loving way, to join with them in extending to their daughter the welcoming greeting that we all owe to each other.