In 2013 Emily Rapp published Still Point of the Turning World, a memoir and philosophical meditation about her son’s diagnosis with and eventual death from Tay Sachs disease. Tay Sachs is caused by a devastating genetic mutation and has no treatment and no cure. Over the course of two years Ronan lost the ability to see, eat, and interact with his world. He also suffered from severe seizures as his brain deteriorated. He died before he turned three, meeting the normal life expectancy for a baby diagnosed with this horrible disease. Rapp was tested for the genetic mutation for Tay Sachs when she was pregnant with her son, but because she carried a rare form of the mutation—and the genetic test only looks for the more common mutation carried by Ashkenazi Jews and French Canadians—the test failed to detect that she was a Tay Sachs carrier. Her husband, who is Jewish, did carry the more common Tay Sachs mutation, but because a diagnosis of Tay Sachs requires receiving the mutation from both parents, Rapp and her husband did not know that their son was at risk for the disease.

Rapp’s telling of her story is heart wrenching but also beautiful and poignant and steeped in the apparent love she has for her son. It’s for all these reasons that disability studies scholar Rosemarie Garland Thomson uses it as a primary example to argue that disability is worth conserving and that to not conserve it is a form of eugenics.¹ The memoir is an example for Garland Thomson of how “suffering expands our imagination

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² I only found one mention of abortion in her essay, on page 355.
about what we can endure” (355). She sees Rapp’s experience, what she calls “her careful balancing of suffering’s costs with the benefits of the ‘blissful’ love Ronan begets” as an example of a counter-eugenic logic (her term) because Rapp is able to simultaneously embrace both the pain and joy that Ronan brings. For Garland Thomson these contradicting emotions, however difficult, are what disability has to offer the human experience, and she mourns the loss of diversity she imagines would result if fetuses, even fetuses with Tay Sachs, were aborted — a word I should note she rarely uses in her essay.²

Rapp’s memoir does an extraordinary job of capturing her feelings about Ronan’s diagnosis. She writes:

Ronan was mine. Mine and Rick’s. Of course we would have done anything to help him, to save him, but we didn’t want him to be another different baby. We couldn’t imagine not having had a part in creating him, or not having known him, or loved him fiercely. We weren’t running away from him or rushing out of any rooms. We stayed put. And we never wanted him to be perfect. We wanted him to live.” (69)

As you can hear in this quotation, Rapp and her husband Rick want to save their son from his devastating disease, and yet, as the book reflects, they also embrace the experience of raising Ronan as Ronan—no matter how painful and difficult that is. And it’s because of that acceptance that Garland Thomson turns to the memoir for an example of how disability broadens humanity and should be conserved.

² I only found one mention of abortion in her essay, on page 355.
Garland Thomson isn’t the first or only disability studies scholar to make this claim.³ Adrienne Asch and Erik Parens published an anthology in 2000, *Prenatal Testing and Disability Rights*, devoted to the argument that prenatal testing which results in the abortion of fetuses considered to have abnormal genetic make up is a form of discrimination against people with disabilities. And in 2013, Alison Piepmeier published an essay in *Feminist Studies* arguing that to abort a fetus with a potential disability—she focuses on Down Syndrome—discovered through prenatal testing is a form of eugenics that limits human diversity.⁴ This argument has recently become especially relevant as new forms of prenatal testing have emerged that allow women to know earlier than ever whether their fetus has a genetic mutation, and perhaps even more significantly, these tests are much less invasive than earlier forms of prenatal testing that carried the risk of miscarriage.⁵ Yet importantly, all four critics not only share the same underlying suspicion of prenatal testing, they also make explicit their commitment to reproductive justice and access to abortion. It’s the latter position, they insist, that sets them apart from anti-abortion activists who often use disability rights as one way to lobby against access to abortion. While all four critics believe that their commitment to reproductive justice can co-exist with their critique that women who choose to abort fetuses with potential disabilities are prac-

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³ This also isn’t the first time she makes this argument in her own work. In her groundbreaking book on physical disability in American literature and culture, *Extraordinary Bodies*, she briefly notes in the introduction that prenatal testing risks eliminating disability. See also her argument in the online journal *Biopolitics*. The article I focus on here, however, presents one of her more thorough positions on prenatal testing, even though she rarely invokes that term or mentions abortion.


⁵ I’m referring to free cell DNA testing, which can locate fetal cells in the mother’s blood and test for mutations that cause Down Syndrome and other trisomies, as well as some chromosomal duplications and deletions.
ticing a new form of eugenics, this paper will show how they inadvertently employ the same rhetoric they reject when making this accusation.

Rapp views abortion’s relationship to disability differently. A year before Ronan’s death, Rapp published an essay in *Slate* where she wrote in unequivocal terms, If I had known Ronan had Tay-Sachs [when she was pregnant], I would have found out what the disease meant for my then unborn child; I would have talked to parents who are raising (and burying) children with this disease, and then I would have had an abortion. Without question and without regret, although this would have been a different kind of loss to mourn and would by no means have been a cavalier or uncomplicated, heartless decision. I'm so grateful that Ronan is my child. I also wish he'd never been born; no person should suffer in this way—daily seizures, blindness, lack of movement, inability to swallow, a devastated brain—with no hope for a cure. Both of these statements are categorically true; neither one is mutually exclusive.  

In her essay Garland Thomson acknowledges that Rapp would have had an abortion if she had known about her son’s diagnosis, and yet, she dismisses Rapp’s own argument that Tay Sachs should be eliminated in order to use her memoir as evidence for her critique of prenatal testing and an example of a counter-eugenic logic. Implied in her critique is the argument that if Rapp had aborted her fetus, if she had learned about the Tay Sachs diagnosis during pregnancy, then she would have been engaging in eugenics.

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7 For the rest of her argument, see: [http://www.slate.com/articles/double_x/doublex/2012/02/rick_santorum_and_prenatal_testing_i_would_have_saved_my_son_from_his_suffering_.html](http://www.slate.com/articles/double_x/doublex/2012/02/rick_santorum_and_prenatal_testing_i_would_have_saved_my_son_from_his_suffering_.html)
The word *eugenics* often conjures images of Nazi concentration camps, pseudo-scientific comparisons of cranial capacity that supposedly proved a hierarchy of races, and rulings like the notorious 1927 Supreme Court Case *Buck v. Bell* where Oliver Wendell Holmes Jr., who was then Chief Justice of the court, upheld a Virginia law that mandated forced sterilization for anyone who was deemed “socially inadequate.” The word *eugenics* comes from the Greek word *eugenes* and was first coined in 1883 by Francis Galton, who was interested in studying the inheritance of genius through generations. Galton, a cousin of Charles Darwin’s, called his theory “practical Darwinism,” and he hoped his ideas would influence the elite and educated to reproduce more in order to better society. The emergence of eugenics, however, can be traced further back than Galton to at least Thomas Malthus who, writing in 1798 (“Essay on the Principle of Population”), argued that without population regulators human numbers would grow exponentially around the world. He asked whether this growth might lead to a degradation in the quality of human life, as the world contained more people than it could support. In 1852, Herbert Spencer reversed Malthus’ argument by theorizing that the competition for resources advanced human civilization through competition, and to describe this phenomenon he coined the term “survival of the fittest,” which became a catchphrase in support of eugenics. By the early twentieth century, eugenics was embraced as a legitimate field of scientific study in the United States.

Given this history, what are the implications of calling the abortion of a fetus with Tay Sachs eugenic? For that matter, what are the implications of accusing any woman who chooses to have an abortion because of the results of her prenatal genetic tests of engaging in eugenic practices? Rapp states in unequivocal terms that in an ideal world her
son would never have been born. He suffered horribly, and she and her husband suffered horribly as well. When Garland Thomson draws on their experience as an example of suffering for the good, for the diversity of human kind, and for a counter-eugenic logic, she insults the profundity of their experience—and their misery. On a more fundamental level, Garland Thomson, Piepmeier, Asch, and Parens use of the word eugenics is anachronistic. Nikolas Rose, known for his biopolitical analyses of contemporary scientific technologies, argues that describing prenatal genetic testing as eugenics misunderstands the term and its history. According to his argument, prenatal testing—and other forms of genetic testing labeled as preventative medicine—is “individualized, voluntary, informed, ethical, and preventative” and organized around the “pursuit of health” (55). Even as Rose is aware that these tests work to “eliminate differences coded as defects” (55), he insists that they cannot be called eugenic because, as he explains, eugenics occurs primarily under the auspices of the state—that is, with persuading the state to set laws that shape the population in order to form a nation-state with a sought-for identity. Furthermore, he points out that prenatal genetic testing (and it follows, abortion of a fetus with potential disabilities) is never compulsory but voluntary. As he describes, “Seldom, if ever, are the actions or judgments of any of the actors in these practices shaped by the arguments that the nation is somehow weakened geopolitically by the presence of ‘diseased stock’ within the population” (69). In other words, prenatal testing for him can’t be a form of eugenics because its justifying rhetoric is personal, individualized and doesn’t echo early-twentieth-century claims about national consequences of reproducing “badly.” Following Rose’s argument, Rapp’s experience can’t be counter-eugenic because its terms are deep-

ly personal. Nowhere does Rapp argue that all fetuses with Tay Sachs should be aborted or that her son challenges the reproductive decrees of the state. On the other hand, Garland Thomson’s reasoning attempts to create a “feel good” politics that situates disability as a form of national diversity.¹² Rapp’s writing about her son never tries to find any good in his suffering. His suffering, she lets us know explicitly, is bad—awful, painful, unbearable.

Eugenics is a powerful word because it has an atrocious history, and when Garland Thomson (and others) draw on its power to make their claims, their arguments emphasize how people with disabilities have been marginalized, excluded, and eliminated. I see the compulsion to use this language because it makes people listen, and it draws attention to critical issues about living with disability in the twenty-first century. At the same time, it has the potential to shame women seeking to find answers about their reproductive lives and to limit their reproductive options. It builds on the shame that already surrounds abortion in the United States. It doesn’t take into account the lived pain of Rapp’s son Ronan, and it doesn’t acknowledge the economic repercussions of having a severely disabled child with a limited life span. Yet disability—in all its myriad forms—is also stigmatized in the United States. Ultimately, it’s this stigma, the valorization of the so-called normal, healthy body that Garland Thomson and others working in disability studies are hoping to address. Garland Thomson doesn’t use the language of biopolitics, but her arguments gesture toward the recognition that biopolitics govern our behaviors, our understandings of our bodies, our desires for normality, and our fears of embodied

difference. Bodies in the twenty-first century are constantly managed, and that management often works on a molecular level that is obsessed with how our bodies function physiologically.

The key point for me here is that a shared biopolitical logic governs both the marginalization of bodies with disabilities and reproductive bodies. Just as the healthy body—the idealized body free of any inhibiting disability (the fantastical body)—is held up as the norm, the reproductive body that can produce children without economic, social, physical, and emotional constraints is similarly prized. When Garland Thomson critiques prenatal testing (and presumably the abortions that follow) because—as she argues—it deprives us of diversity, she ends up replicating the underlying logic behind eugenics: Women need to reproduce for the benefit of the nation-state. In other words, our reproductive choices have repercussions that exceed us. In an argument that seems to have endless variations, Garland Thomson once again gives women’s reproductive lives a greater responsibility by arguing that women’s bodies and reproductive choices can be held responsible for whether a more utopic (“diverse”) future might arrive, just as eugenic scientists and politicians argued at one time when justifying laws for forced sterilization and limited access to contraceptives. Even as Garland Thomson resists subscribing to the biopolitical norms that shape how disabled bodies are valued, she enforces the norms that dictate how women should behave reproductively. If Rapp’s memoir counters anything, it’s not because “suffering expands our imagination about what we can endure” (which is at best a horrible cliché), but because her memoir refuses to turn her son’s suffering into a simple lesson or moral tale about diversity, disability, reproduction, and genetics. In her words, “The meaning of Ronan’s life was not to teach me; we often say this
about people who defy our notions of normal and I find it pathetic, patronizing and a way of distancing ourselves from our own fragile bodies and tenuous lives” (114).