Crippling Neoliberal Futurity: Marking the Elsewhere and Elsewhen of Desiring Otherwise

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In this article I argue that it is necessary to crip neoliberal futurity so as to enable the flourishing of critical practices of an elsewhere and elsewhen of disability. The withering of some disabled lives and the capacitation of others are a result of neoliberal material and discursive processes that orient and imagine disability as a life without a future unless capacitated through practices of biocapitalism, such as through cure or body/mind enhancement technologies and procedures. I argue that neoliberal futurity organizes disability in such a way as to make disability intelligible through the suffering disabled child that is never imagined or anticipated to grow up or have a life worth living. At the same time, neoliberal futurity also speaks to the difference of the futures imagined for some disabled children: biocapitalist futures, premised on the hope of overcoming disability through care or body/mind enhancement.

Introduction

"My future is written on my body," Alison Kafer writes on the opening page of Feminist, Queer, Crip (2013, 1). Resisting the way in which her wheelchair, burn scars, and gnarled hands enable some to mark her future as a life of “pain and isolation,” “a life not worth living,” and “a future no one wants,” Kafer instead offers a “politics of crip futurity” as a way of imagining and orienting to her future otherwise, one that is “ripe with opportunities” (1-3). If, as Rosemarie Garland-Thomson argues, disability remains unexpected in our world because we do not imagine disabled people as having tractable futures (2012, 351), then crip futurity becomes an important site to both imagine and materialize tractable disabled futures. Pushing against this lack of future, Kafer yearns for an “elsewhere” and “elsewhen” (3) of crip futurity—of desiring disabled futures otherwise—while remaining aware, following Nirmala Erevelles (2011), of the inequitable social and material conditions under which the desire for crip futurities is produced, circulated, and celebrated. That is, through practices of neoliberal biocapitalism, the lack of tractable futures for some disabled people works alongside the tractable futures of enhanced or capacitated disabled people, embedding crip futurities within the inequitable inclusion practices of neoliberalism. It is precisely at this juncture that I wish to consider the contemporary social, political, and economic constraints of desiring disabled futures otherwise by tracing the ways in which some disabled futures have already gained traction, albeit at the expense of others. In other words, I argue that the material discursive practices of neoliberal biocapitalism have enabled the tractability and flourishing of particular disabled futures while other disabled futures remain unanticipated, unexpected, and undesired.

In this article, then, I argue that it is necessary to crip neoliberal futurity so as to enable the flourishing of critical practices of an elsewhere and elsewhen of disability. The withering of some disabled lives and the capacitation of others result from neoliberal material
and discursive processes that orient and imagine disability as a life without a future unless capacitated through such biocapitalist practices as cures or body/mind enhancement technologies and procedures (see Fritsch 2015). Neoliberal futurity organizes disability in such a way so as to make disability intelligible through the suffering disabled child who is never imagined or anticipated to grow up or have a life worth living. Through neoliberal futurity, this suffering disabled child is figured as the negation of the future, or as a subject with no future. At the same time, however, neoliberal futurity also speaks to the difference of the futures imagined for some disabled children: biocapitalist futures, premised on the hope of overcoming disability through cure or body/mind enhancement.

Building on Lee Edelman’s (2004) critique of “reproductive futurity” that privileges the Child as the image of the future, I contend that neoliberal futurity produces the figure of the disabled child that is productive—as far it creates varied discursive and affective economies aimed at preventing life, ending lives, capacitating some bodies, and re-investing a caring public in biocapitalism—and also re-inscribes the hope for a future without disability or, at least, a future in which disability no longer seems to be a difference that matters. That is, I show that it is at the confluence of this double lack-of-futurity—disabled children without futures and a future without disability—that some disabled adults become unanticipated lives left to wither while others become capacitated as inspirational, hopeful, and progressive success stories of neoliberal inclusion. By reading across a number of discursive and material sites, I show through a breadth of examples the recurring logic of neoliberal futurity in its variance and repetition, marking neoliberal futurity not as a project of homogenous actions and desires, but rather as productively diverse in the ways in which it participates in a double lack-of-futurity for disability. I explicate how some disabled people flourish in the future precisely because their futures gain traction through neoliberal biocapitalist practices and that these tractable futures demand that others have no future.

Reproducing Neoliberal Futurity and the Disabled Child

In No Future: Queer Theory and the Death Drive, Lee Edelman (2004) argues that the contemporary political order privileges heteronormativity by inciting the Child as the image of the future (2-3). Edelman calls this child-centered “ideological limit” and “organizing principle” of social relations “reproductive futurism,” a cultural and political way of investing in a better future for the sake of our children (2). For Edelman, the field of politics is steeped in the figure of the Child, so much so that “the image of the Child invariably shapes the logic within which the political itself must be thought” (2) and is the “fantasmatic beneficiary of every political intervention” (3). He notes: “We are no more able to conceive of a politics without a fantasy of the future than we are able to conceive of a future without the figure of the Child” (11). Thus, within this heteronormative logic, a better future is always a better future for the Child. Edelman comments that refusing this mandate made by political institutions to compel the collective reproduction of the Child must “appear as a threat not only to the organization of a given social order but also, and far more ominously, to social order as such, insofar as it threatens the logic of futurism on which meaning always depends” (11). The ever “lengthening shadow” of the Child “terroristically holds us all in check and determines that political discourse conform to the logic of a narrative wherein history unfolds as the future envisioned for a Child who must never grow up” (21). While Edelman is largely interested in the ways in which reproductive futurism figures the Child within contemporary American political
discourse, my work builds on Edelman’s critique to mark the ways in which neoliberal futurity mobilizes the suffering disabled child to create a future in which the child never grows up, or only grows up through the practices of biocapitalism.

Thinking through Edelman’s critique of reproductive futurism, it is important to consider how the figure of the suffering disabled child organizes the way in which the future of disability and disabled people are imagined within the ongoing neoliberalization of psychic and material life in North America. That is, it is important to consider the role played by the figure of the suffering disabled child within what can be called neoliberal futurity.

Rather than a temporal direction of time, neoliberal futurity speaks to a shared social imaginary of progress that underwrites capitalist relations, a frame of thinking made possible by the mode of production and the ongoing pursuit of surplus value. Franco Berardi terms this imaginary of progress—that the future will be better than the present—the “myth of the future,” a myth that is not “a natural idea” but rather is “rooted in modern capitalism” and the “bourgeois production model” (2011, 18). Neoliberal futurity—based on an economy of always more surplus value to extract, always new markets to develop, always new ways to download social responsibilities onto individuals, always evermore ways to exploit the many in order to benefit the few—requires a child that will overcome the odds and rise up to meet the new demands of the economy. Neoliberal futurity, then, inspires parents to invest—and go into debt—to produce an entrepreneurial kindergartener that eats the right food, goes to the right school, and has all the right opportunities available to them so as to best prepare them for the hypercompetitive, individualistic future (for example, see Webb 2013).

Turning to Berardi’s myth of a better future highlights the role of biocapitalism in the production of neoliberal futurity. Biocapitalism marks the ways in which, since the 1970s, the neoliberalization of the economy and social relations emerged alongside developments in the life sciences and biotechnological industries, promising a new and healthier future that could overcome the market-growth limitations of both the Earth’s finite resources and Keynesian economic and social policies (Fritsch 2015). As biocapitalism organizes the life sciences, it depends upon neoliberal practices of deregulation, privatization, managing risk, and financial speculation that mobilize hope for a better future. In this way, biocapitalism signifies the ways in which scientific knowledge is co-produced materially and discursively alongside the political and economic practices of neoliberal capitalism (Sunder Rajan 2007).

Biocapitalism invests in life at both the micro and macro levels to produce neoliberal political subjects. Biocapitalism extends Michel Foucault’s concept of biopolitics as a practice of governance that brings “life and its mechanisms into the realm of explicit calculations” (1978, 143), engaging not just with individuals or populations, but with all aspects of life itself, including cells, molecules, genomes, and genes (Helmreich 2008). Bringing “life and its mechanisms into the realm of explicit calculations” (Foucault 1978, 143), happens in part through ongoing developments in pharmacogenomics, or “personalized medicine.” Pharmacogenomics enables the individualization of “risk” as an embodied biomarker that can be used to target individuals for ongoing therapeutic interventions (Dumit 2012, Fritsch 2015, Sunder Rajan 2007). Children can be enhanced and capacitated not only through an array of extracurricular activities and technologies, but also through individualized forms of pharmacogenomics and risk surveillance that enhances their bodies through, for example, tailored drug regimes that ensure an optimal microbiome and gut health and improved brain performance. These practices are future oriented, for not only does biocapitalism promote technoscientific innovation as a way to overcome the limits of vulnerable bodies, but its material and discursive practices also incite a child that can be enhanced and capacitated in
such a way as to meet the current and future demands of the neoliberal economy.

While Edelman (2004) accounts for the ways in which the Child as the image of the future is central to the notion of progress, what he does not account for is how this Child relies on an economy of disability that is deeply entrenched in neoliberal practices of biocapitalism. That is, neoliberal practices not only produce disability or are complicit in rising rates of disabling conditions through unsafe labour practices, war, and the systematic dismantling of the welfare state, but neoliberal practices also demand that some succeed at the expense of others. In this way, we cannot account for neoliberal futurity without addressing disability.

Thus, while Edelman (2004) is correct in asserting that the contemporary political order favours heteronormativity in the ways in which it incites the heterosexual Child as the image of the future, I argue that this image of the Child as the future also continuously incites compulsory enhanced-bodiedness/mindedness, as the child of reproductive futurism is not only able-bodied, but must also be better than able-bodied or able-minded. As Robert McRuer points out, “everybody,’ after all, or so the saying goes, ‘wants a healthy baby’” (2008). Edelman’s sharp and scathing critique of reproductive futurity is important, as is McRuer’s argument that Edelman’s Child is able-bodied. Yet what neither Edelman or McRuer elucidate is how reproductive futurity relies on both a capacitated and enhanced Child and also for some disabled children to grow up at the expense of others whom dominant structures never intend to grow up. While McRuer is right to point out that no child can fully embody the desirable able-bodied and-minded Child and, thus, sets up disability as the impediment to a desirable future, I argue that the better-than-able-bodied-and-minded Child requires some capacitated disabled children to flourish at the expense of other disabled children in order to give meaning to the figure of the Child.

There is, then, an important ambivalent tension within neoliberal futurity; the disabled child is at once a figure with no future while at the same time also a figure of neoliberal futurity mobilized through biocapitalism, cure, and enhancement. Therefore, I argue that we are deeply invested in narratives of suffering children, but some of those children are always supposed to remain children, never growing up, while others are celebrated, enhanced, and capacitated precisely because they can be made to fit into the neoliberal biocapitalist promise of the future.

The “End of Suffering” and “No Hope for the Future”

That disabled children have no future and are the denial of the future, as McRuer (2008) argues, is perhaps most evidenced in instances of parents “mercifully” killing their disabled children to end their suffering. Stories of such incidences litter news and blog sites in which parents undergoing significant stress and hardship trying to raise disabled children come to believe that there is “no hope for a future” (Smith 2013). For example, on April 22, 2014, Tania Clarence suffocated to death her three disabled children in a move “to end their suffering” (Davies 2014). Max and Ben, Clarence’s three-year-old twin sons, and Olivia, her four-year-old daughter, all had Spinal Muscular Atrophy (SMA) Type 2, which is described by the media as “a life-limiting progressive disease” that can “cause fatal respiratory problems” (Davies 2014). The children’s nanny, Jadna Coelho, found them dead in their bedrooms of their £2 million family home in New Malden, England (BBC 2014). Tania Clarence’s husband, Gary, an investment banker, and their able-bodied eldest daughter were away on holiday at the time.

In October 2014, murder charges against Tania Clarence were dropped after she
entered a plea of “manslaughter by diminished responsibility.” The Crown Prosecution Service found Clarence to be “suffering from a major depressive episode at the time of the killings which amounted to an ‘abnormality of mind’” (Davies 2014). Zoe Johnson, the Prosecutor in charge of the case, describes Clarence as holding the “firm belief that the quality of her children’s lives was more important than their longevity” (Davies 2014). This belief, the Prosecutor argued, is “entirely understandable” (Davies 2014). Defence attorney Jim Sturman remarked that Clarence “was manifesting stress throughout the life of the children by their suffering, and caring for three children with this condition was exhausting, distressing, debilitating and turned out to be overwhelming” (Davies 2014). As a result, the defence argued that it is “understandable” that Clarence did what she did because she “had no hope for the future” (Smith 2014).

Tania Clarence’s distress and lack of hope for the future for herself and for her children is marked throughout her court appearance and in the media as “understandable” precisely because of the ways in which ableism and neoliberal futurity work together to make intelligible the suffering disabled child with no future. Clarence’s murder is “understandable” despite the financial affluence of the family that enabled them to fully renovate their expensive home, hire both a nanny and a maid, and allowed Clarence to leave her job as a graphic designer to stay home to help care for the children. Indeed, despite Clarence’s financial comfort, in a letter she wrote her husband two days before the killings she noted that, “I cannot face going down this path watching Liv and the boys continue to get weaker […]. No matter what we do, it will never be enough” (Wilkes 2014). Later, in another letter addressed to her husband written after killing her two sons but before killing her daughter, Clarence wrote: “The only thing giving me the motivation to continue is the belief that the boys are already playing up in heaven like they could never play here” (Wilkes 2014).

Only through death can a future be imagined for these disabled children. Despite having financial security, access to healthcare, and domestic help, Clarence could project no future for her disabled children. Further, by killing her disabled children, Tania Clarence produces a future without disability and, thus, fulfills the thinking that disability has no future.

Jerry’s Kids

The cultural logic that there are no disabled futures, one that makes Tania Clarence’s actions “understandable,” rubs up against biomedical advances in care for SMA. As some news stories have noted, “most people with the condition go on to live productive adult lives” (Smith 2014). Clarence was sentenced on November 18, 2014 to a mental-health treatment program. Just days before Clarence’s sentencing, in Southern California, Cure SMA, formally known as Families of Spinal Muscular Atrophy (FSMA), held a “Gala of Hope […] with one goal: To fund a cure for Spinal Muscular Atrophy” (FSMA 2014). Children are the main focus of Cure SMA’s literature and programming and by curing SMA those children will once again have a future that SMA denies them. As Cure SMA’s slogan puts it: “We can see a future without SMA” (Cure SMA 2014). The futureless future of SMA thus comes in many forms, whether through cure or what has elsewhere been deemed “mercy killing” (Evans 2014).

The simultaneous play of no future that mobilizes hope for a cure and also posits no future for disabled people and disability at the same time imagines a future for some disabled children. This dynamic is nowhere more evident than in the Jerry Lewis Labour Day Telethon. Indeed, the Jerry Lewis Labour Day Telethon has popularized cultural understandings of
disabled children as both a site of hope and overcoming disability as well as a site of disabled suffering and tragedy.

The annual 22-hour Jerry Lewis Labour Day Weekend Telethon was first broadcast in 1966 to raise money for the Muscular Dystrophy Association (MDA), whose goal is to fight neuromuscular disease. Broadcasting over 1,000 hours of live television hosted by Jerry Lewis and featuring an array of celebrities and entertainers, the telethon has been deemed the “most successful fund raising event in the history of television,” raising over $2 billion over its first 46 years of broadcasting (MDA 2014). In his 45 years hosting the telethon, Lewis worked toward getting “one dollar more” than the previous years so as to get “closer than ever to a cure” for those he called “Jerry’s kids.” As a result of such enormous fundraising efforts, the MDA became the first non-profit organization to receive a “Lifetime Achievement Award” from the American Medical Association “for significant and lasting contributions to the health and welfare of humanity” (MDA 2014). Lewis himself was also nominated for the Nobel Peace Prize in 1977 as a result of his work with the MDA (Walton 1997, 65).

The MDA telethon produces disability as “a fate worse than death” and disabled people “suffering” from Muscular Dystrophy as people “waiting for a cure, without which their lives are worthless” (Johnson 1992). For example, in the 1973 telethon, Lewis held up a child with Muscular Dystrophy and announced: “God goofed, and it’s up to us to correct His mistakes” (Wiener 2011), affirming the belief that disability is a deviation and a mistake that must be corrected. During the 1992 telethon, Lewis stated: “My kids cannot go into the workplace. There’s nothing they can do. They’ve been attacked by a vicious killer. I’m begging for their survival” (Hershey 1993). Statements such as these reaffirm the popular cultural belief that disability is a “monolithic fact of the body” (Kafer 2013, 3) that stops people from living their lives and that it is disability that needs to be cured rather than dominant social structures or relations.

The MDA telethon seeks to “pry open wallets” through the objectification of suffering children, despite the fact that two-thirds of MDA’s clients are adults (Hershey 1993). The telethon does not represent “the real lives of people” but rather works to “paint a picture of a victim so tragic, and at the same time so cute and appealing, that viewers will be compelled to call in a pledge” (Hershey 1993). While appearing tragic and cute, the “victim” must also appear “utterly unable to help him/herself, so that the giver can gain a personal sense of virtue and superiority from the act of giving” (Hershey 1993). Additionally, the “victim” must display a form of “courage” that results in a depreciation of oneself, an acceptance of “other people’s versions of one’s own reality,” and a rejection of the value of oneself as a disabled person in favour of “an eagerly anticipated cure” (Hershey 1993). All this is done to “encourage the assumption that life with a disability is a life scarcely worth carrying on with, except for the generosity of Jerry Lewis and everyone involved in the telethon” (Hershey 1993). Reviewing hundreds of hours of telethons, disability historian Paul Longmore found few segments featuring disabled adults, reinforcing “the Tiny Tim persona” as “central to framing the cultural, social, and political meaning of disability. The charities depicted the representative disabled person as a vulnerable child, one of ‘the most weak’” (2013, 38).

Starting in 1981, some of “Jerry’s kids” became “renegades” who called themselves “Jerry’s Orphans” and began protesting outside of telethon filming locations with placards calling for an end to telethons, “rights not pity,” and demanding support for universal healthcare and a national research agenda (Walton 1997). Protestor Evan Kemp notes that the telethon “makes disabling conditions seem overwhelmingly destructive,” emphasizing “the desperate helplessness of the most severely disabled. In doing so, it reinforces the public’s
tendency to equate handicap with total hopelessness” (Kemp 1981). As Laura Hershey (1993) notes, “the telethon encourages viewers to project their own worst fears onto people with muscular dystrophy,” encouraging them to “imagine what it would be like if your child couldn’t play baseball.” Further, “families are described as ‘courageous’; and they all seem to bear total responsibility for the care and support of the person with MD,” marking disabled bodies as burdens.

Responding to disability rights activists, in the 1990s the MDA began changing some aspects of its telethon. It began showcasing disabled adults and significantly shortened the programming to just a few hours rather than 22 consecutive hours. On May 16, 2011, Jerry Lewis announced his retirement (MDA 2014). In May 2015, citing the need to adapt to changes in “television viewing and philanthropic giving,” MDA transitioned away from the telethon as a means to raise money and began focusing on “making muscles move” through increasing its direct marketing initiatives, “endurance fundraising” initiatives such as running marathons and “Muscle Walks,” and fostering “personal shows of strength” through online videos and ad campaigns (MDA 2015). MDA President and CEO Steven M. Derks noted, “In the last few years, the show was adjusted to reflect changes in viewership and donor patterns, and last summer’s Ice Bucket Challenge once again affirmed for us that today’s families, donors and sponsors are looking to us for new, creative and organic ways to support our mission” (MDA 2015). The MDA’s slogan “Making Muscles Move” is readily in juxtaposition with the wasting muscles of people with MD that fail to move without the promise of a cure or medical enhancement.

These new initiatives rebrand the suffering child and the adult who overcomes disability as participants in an economy of always more enhancement, always more treatment options, always more adaptive equipment. The suffering child and the overcoming adult are sites of medical consumption, where the goal is not merely to cure so as to have an able-body, but to cure and enhance the body, to end the suffering of muscle disease through enhanced and capacitated strength, through technologies and treatments that create better-than-able-bodies. The MDA telethon produced and promoted the suffering of disabled children as an object of consumption and of pity while also marking these children as having no future. A future only becomes possible for these children through cure and enhancement; without cure and enhancement, or without the possibility of hope for a cure, there is no future for disability.

“Yes, there’s hope for future children”

In the New York Times bestselling memoir, The Still Point of the Turning World (2013), Emily Rapp recounts her experience with her son Ronan, diagnosed at the age of nine months with Tay-Sachs disease, a “rare and always fatal” degenerative genetic condition “with no treatment and no cure” (1). Tay-Sachs “causes a slow developmental regression into paralysis and sensory loss that is irrevocably fatal by the age of about three,” foreshortening “an entire life-course to a chillingly compact arc” (Garland-Thompson 2012, 349). For Rapp, Tay-Sachs is “the shittiest disease of all time” (2013, 33): “There is no cure for Tay-Sachs, no arguing with biology. We understood that our son would gradually regress into a vegetative state within the span of one year, and that this slow fade would progress to his likely death before the age of three” (2013, 24). Before getting Ronan’s official diagnosis, Rapp comments, “I had been worried for some time. Ronan was experiencing development delays, missing important milestones [...] He was the same at nine months old as he had been at six months” (2013, 1). Rapp was concerned because Ronan was not progressing as she expected he would.
Rapp acknowledges that if she had been aware that her son would be born with Tay-Sachs she would have selectively aborted her pregnancy to prevent the suffering of both her son and her family. Ronan’s diagnosis came as a surprise to Rapp as she had been screened for the condition during the early stages of her pregnancy. However, she only had the standard screening test for Tay-Sachs that detects the nine most common mutations rather than testing for the more than 100 known mutations (2013, 3). Unlike most children now born with Tay-Sachs who are “born to parents who didn’t know they had anything to worry about” (2013, 78), Rapp believes that through genetic screening she had done her part to “cover all the bases, get the results, to know” (2013, 78).

As Rapp had taken precautions to manage potential genetic risks, Rapp sees in her son a life that has already failed. On the drive home from the doctor’s office where they received Ronan’s diagnosis, Rapp notes that Ronan, giggling in his car seat, is “oblivious to his wretched future” (2013, 7). She imagines herself untangling his DNA to “restitch it, rebraid it, fix it, make it right, take it back somehow, change the odds” (2013, 88). For without this fix, this re-braiding of Ronan’s DNA, Rapp and her husband find themselves without hope. Rapp asks: “How do you parent without a future[?] Could it even be called parenting, or was it something else, and if so, what?” (2013, 11). She comments that parenting for the sake of parenting contradicted every bit of parenting advice she had ever read, for “parenting advice is, by its very nature, future directed” (2013, 13). With Ronan facing a foreshortened future, Rapp’s understanding of what it is to parent is displaced. Rapp had imagined that Ronan would be “physically fearless,” an “adventurous eater,” “fun but level-headed, loyal and fair and smart” (2013, 15). He would be “generous and gorgeous” (2013, 16). Yet as Rapp comments, whatever she did for Ronan would not matter: “organic or nonorganic food; cloth or disposable diapers; attachment parenting or sleep training: breast milk or formula—all the decisions that mattered so much to me in the first few months of his life, he was going to die” (2013, 16). No matter how much Rapp invested in doing the “right” things to ensure the best future for Ronan (including genetic testing), his foreshortened future left Rapp to confront neoliberal failure. Rapp was promised a particular future if she negotiated it properly and as Ronan failed to meet normative markers of growth and development, the promise was not fulfilled.

Rapp’s neoliberal failure leads her to lament: “I’d never experience with Ronan so much of what I’d been looking forward to as a mom: marveling as he acquired language, teaching him to ski, traveling with him to all of the wonderful places I have lived, helping him learn how to be a unique person in this mad world” (2013, 69). Rapp consoles herself at times by reassuring herself that in dying young Ronan would “never experience shame, regret, fear, self-loathing, worry, anxiety, or stress [...]. Ronan would never wish himself to be different” (2013, 69-70); yet she nonetheless continues to wonder “about all the things” Ronan “might be or become” if it were not for Tay-Sachs (2013, 75). Indeed, that all investment in Ronan can only be temporary—present and not future-oriented—unsettles conventional neoliberal paradigms. That the promises of successful futures that neoliberal futurity offers—through getting a jump on other children in choosing organic food or cloth diapering, or through starting baby sign language or music classes to develop the brain—will never lead to neoliberal success for Ronan is one of the biggest challenges Rapp struggles with throughout her memoir.

Rapp hangs in temporal ambivalence, teetering back and forth between wanting and imagining a future that will not come while also trumpeting living in the moment. Rapp reluctantly comes to face that her “task was not to prepare my son for his future, but to make each day and each moment count” (Rapp 2014a). Battling these feelings, Rapp asserts: “I wasn’t interested in music class or swimming lessons for Ronan because I hoped he would manifest
some fabulous talent that would set him, and therefore me, apart. I wasn’t searching for heaps of praise about what an amazing mom I was. I was interested in creating experiences for Ronan that would make him happy” (Rapp 2013, 20). Making Ronan happy was not about any future potential: “There was nothing he needed to prove or do or become. He could stay a beautiful acorn; he didn’t need to grow into a tree or realize his potential [...]. No pressure to be quicker or better or smarter than the other kids” (2013, 75). Garland-Thomson argues that Tay-Sachs provides an example of disability that “demands that we all might imagine a subject without a future life trajectory perpetually managed in the present moment” (2012, 353), echoing Rapp’s position that Ronan could “stay a beautiful acorn” (2013, 75). And yet, while the “we” in Garland-Thomson’s statement is meant to interpellate the non-disabled to live as if they also have no certain and predictable future (echoing again Rapp’s “beautiful acorn” that suggests the same live-in-the-now outlook), cultural artefacts such as Rapp’s memoir re-inscribe disability as having no future while also capacitating some forms of enhanced disabled futures. Rapp’s account marks disability as both “no hope for a future” (Smith 2013) but also the difference of disability: while Tay-Sachs is no future, not all disabilities offer no future. Both iterations work alongside the figure of the Child as the future.

While Rapp desires a future that is not possible for Ronan, Rapp simultaneously reinvests in being the mother of a yet-to-be born child. As Rapp’s friends in the Tay-Sachs’s community assure her, “Yes, there’s hope for future children” (2013, 9), and as Rapp herself comments, “After my son Ronan was diagnosed [...] I immediately wanted another child” (Rapp 2014b). Sharing her desire for another child with another Tay-Sachs mother, that mother approvingly comments, “Of course you want to feel life again” (Rapp 2014c). While Ronan is still alive, Rapp begins investigating fertility treatment options that would ensure she did not have another Tay-Sachs child. Upon the birth of her daughter Charolette in 2014, Rapp cautions that she “can live with the joy of new motherhood without losing the memory of loving my son” (Rapp 2014a). Yet Charolette also clearly signals the hope of a non-disabled life and future that extends, as Rapp comments, “long beyond my own and [Charolette’s] father’s” (Rapp 2014a), even if her daughter will never replace Ronan. Rapp’s memoir reinvests her reader in the figure of the Child as the future.

Rapp’s story is not unique in the sense that there is a broad cultural logic of disabled children positioned as having no or foreshortened futures. Thus, while Ronan’s foreshortened future came as a surprise to Rapp precisely because he was born without any indication of disability and because Rapp had been assured through her genetic testing that Ronan would have nothing short of a full future, culturally it is readily acknowledged that disabled children have no future, or that what future they have is undesirable. Ronan, once diagnosed as disabled, is imagined to not have a future not only because of the biological trajectory of Tay-Sachs, but also because of the futureless-orientation to disability that dominates our shared social, political, and cultural understandings of disability. The New York Times best-selling success of Rapp’s memoir speaks to the already circulating discourses about disability, suffering, and a lack of a future.

Share the Power of a Wish

The way in which disability can signal a lack of futurity rubs up against the non-profit organization Make-A-Wish Foundation of America (MWF), which grants the wishes of children with life-threatening medical conditions in order to “enrich the human experience with hope,
strength and joy” (2014). The wish opens up hope for the future of disabled children or disabled futures made possible through medical capacitation.

The MWF was started in 1980 by Arizona customs agent Tommy Austin and police officers Ron Cox, Frank Shankwitz, and Jim Eaves. These officers wanted to help Chris Greicius, a seven-year-old boy who had terminal leukemia. Greicius yearned to be a police officer, and Cox and Austin, along with help from the Arizona Department of Public Safety (DPS), named Greicius an honorary DPS officer before his death on May 3, 1980. After Greicius’ death, a group of DPS officers and friends gathered together to discuss their experience with Greicius and ended up forming the MWF. By 1981, they had raised $2000 and granted their first official wish to seven-year-old Frank Salazar, who also had leukemia. The MWF was later incorporated in 1983 and opened chapters across the US with a mission statement of granting a wish to any child diagnosed with a life-threatening medical condition. In 2013 alone, the MWF granted 14,003 wishes to children with life-threatening medical conditions and has granted over 240,000 wishes since 1980.

The MWF (2014) states that a “wish experience can be a game-changer. This one belief guides us. It inspires us to grant wishes that change the lives of the kids we serve.” The “game-changer” the MWF describes refers to bringing about a renewed hope to the children and their families that they will beat their life-threatening conditions, a renewed hope that often results in making the MWF children more compliant with their medical treatments. The MWF notes: “Health professionals treating them say the wish experience is an important adjunct to medical treatment, and they observe their patients feel better and comply more readily with treatment protocols when they experience their wish come true” (2014a). Granting a wish makes the children “more willing to comply with difficult, but vital, treatment regimens” and enables them to “take back control of their lives, and to keep up the fight against their life-threatening medical conditions” (2014a). As opposed to being solely premised on a lack of hope for the future, the wish is premised upon a child continuing treatment and continuing to have hope through medical capacitation.

The wish is oriented to the future, even though the premise of eligibility for a wish is that the child has no guaranteed future. Indeed, while marking the importance of treatment compliance and instilling hope in the child and their family, the MWF at the same time notes that granting one wish is never enough. They state:

But for every wish granted, another child is diagnosed with a potentially qualifying condition. A child who needs a wish. We all look forward to the day when no more children have life-threatening medical conditions. Until that time, Make-A-Wish remains committed to a vision of granting a wish to every eligible child. Because wishes make very sick kids feel better—and sometimes, when they feel better, they get better. (2014b)

This statement invokes a future orientation full of hope towards a time when no child will be terminally ill or disabled. And yet that time has not come, so it is important to support the work of the MWF in bringing sick and disabled children hope today, for they may not have a tomorrow. This viewpoint is reflected in the MWF trademarked slogan “Share the Power of a Wish” (MWF 2013). Capacitating a life now opens up the possibility of futures of remission or liveable futures through medical compliance. At the same time, this future is premised on the present reality that there is no future for disability. That is, to be eligible for a wish, the child must face having no future. That the child has no future emphasizes the importance of the MWF’s work and invokes anticipation; as they note, “It’s hard not to get excited about our work” (2014c).
Wish-kids are expected to die and granting wishes to these dying children brings hope, strength, and a renewed commitment to fighting life-threatening illnesses. Both fighting life-threatening illnesses and granting wishes involve large sums of capital that are dependent upon children having no future and, thus, are in need of living their lives to the fullest while they still live. Furthermore, disabled futures require renewed investment in medical treatment even if the hope is that such an investment will only be temporary. Through the MWF, the suffering child becomes the hopeful child that must always remain a child. Sharing the “Power of a Wish” is limited to the disabled child—there are no wishes for adults. The hope is that the future of the wish-child is a future of remission or a future of medical enhancement; it is not a disabled future.

Not Fighting for the Children

Edelman’s contention is that reproductive futurism disavows all that threatens to end the future, particularly emphasizing the role of the queer as that which “names the side of those not ‘fighting for the children,’ the side outside of the consensus by which all politics confirms the absolute value of reproductive futurism” (2004, 3). While the Child represents the heteronormative future, the queer can only signify “the negativity opposed to every form of social viability” (2004, 9) and thereby threatens the social order because the queer “raises the spectre of, not just a worse future, but precisely ‘no future’” (White 2013, 23). Edelman calls on queers to embrace the negative and to “fuck the social order and the Child in whose name we’re collectively terrorized” (2004, 29), suggesting that the ethical value of queerness is precisely in “accepting its figural status as resistance to the viability of the social” (2004, 3).

For Edelman, queers who seek gay marriage, military service, or adoption thus “jump on the bandwagon of reproductive futurism” (McRuer 2008) and reproduce “the conditions of queer abjection” (White 2013, 23). Instead, Edelman calls on queers to “acquiesce to the charge that we are society’s worst nightmare and to embrace our figuration as the negative force working against the social order” (McRuer 2008), for “queerness can never define an identity; it can only disturb one” (Edelman 2004, 17). Edelman thus provocatively asks: “while not seeking to refute the lies that pervade […] familiar right-wing diatribes [about our capacity to destroy society], do we also have the courage to acknowledge, and even embrace, their correlative truths?” (2004, 22). While asserting that his anti-social strategy “promises, in more than one sense of the phrase, absolutely nothing” (2004, 5) and further noting that his project is “impossible” (2004, 4), he does argue that embracing queer negativity “can have no justification if justification requires it to reinforce some positive social value; its value, instead, resides in its challenge to value as defined by the social, and thus in its radical challenge to the very value of the social itself” (2004, 6). For “queerness exposes the obliquity of our relation to what we experience in and as social reality, alerting us to the fantasies structurally necessary in order to sustain it and engaging those fantasies through the figural logics, the linguistic structures, that shape them” (2004, 6-7). Edelman suggests that queerness is what can challenge “futurism’s unquestioned good” (2004, 7) and also resist the idea that if there is no baby there is no future, and that without a future, social organization, collective reality, and life itself is undone (2004, 13). Edelman asserts “that we do not intend a new politics, a better society, a brighter tomorrow” and choose instead to “not choose the Child” and “insist that the future stop here,” for the future is “is mere repetition and just as lethal as the past” (2004, 31).

Commenting on Edelman’s negation of the future, Jose Esteban Muñoz writes in
"Cruising Utopia: The Then and There of Queer Futurity: “When I negotiate the ever-increasing sidewalk obstacles produced by oversized baby strollers on parade in the city in which I live, the sheer magnitude of the vehicles that flaunt the incredible mandate of reproduction as world-historical virtue, I could not be more hailed” (2009, 92) by the queer imperative to not fight for the children. Yet Muñoz also notes: “As strongly as I reject reproductive futurity, I nonetheless refuse to give up on concepts such as politics, hope, and a future that is not kid stuff” (2009, 92), for “all children are not the privileged white babies to whom contemporary society caters” (2009, 94). Muñoz further elucidates: “Racialized kids, queer kids, are not the sovereign princes of futurity. Although Edelman does indicate that the future of the child as futurity is different from the future of actual children, his framing nonetheless accepts and reproduces this monolithic figure of the child that is indeed always already white” (2009, 95). In addition to McRuer’s critique of the Child as always already able-bodied, other queer and disability studies scholars have echoed Munoz’s critique. For example, Kafer writes that “this always already whiteness is a whiteness framed by and understood through regimes of health and hygiene” whereby racialized and queer kids cast out of reproductive futurity “have been and continue to be framed as sick, as pathological, as contagious,” marking the co-constitution of race, class, and disability as delimiting reproductive futurity (2013, 32). This conclusion is also echoed in the work of Mel Chen (2011) and Deborah Cohler (2014). Kafer and Muñoz agree that “it is important not to hand over futurity to normative white reproductive futurity” (Muñoz 2009, 95), for “[t]he dominant model of futurity is indeed ‘winning,’ but that is all the more reason to call on a utopian political imagination that will enable us to glimpse another time and place: a ‘not-yet’ where queer youths of colour actually get to grow up” (96). Indeed, Muñoz comments that “[t]he way to deal with the asymmetries and violent frenzies that mark the present is not to forget the future. The here-and-now is simply not enough” (2009, 96), leading Kafer to suggest that the task at hand is to “imagine disability and disability futures otherwise” (2013, 34).

Following Muñoz (2009) and Kafer (2013), it is important to fight for the future, but to do so requires addressing the ways by which neoliberal futurity depends upon both negating the futures of disability while also promoting particular inclusions of disability. Thus, while the ableism that underlies the ways in which Kafer’s future is written on her body and the ways in which disabled lives are not tractable, these accounts do not mark the ways in which neoliberal futurity promotes and capacititates certain disabled lives so as to affirm particular forms of biocapitalism and inclusion that have implications for the way in which disability can become in the world. It is not enough then, to invest in the neoliberal biocapitalist forms of enhanced futures of disabled people. Rather, it is imperative to turn away from the myth of the future that forecloses the possibility of other worlds.

In 2014, Kristin Nelson’s radio documentary told the story of Paige Cunliffe, a 21-year-old woman living in Ontario, Canada who became developmentally disabled after a bout of meningitis at the age of 13 months. For most of Paige’s life her mother Pam was her primary caregiver, but Pam found that she was no longer able to care fulltime for Paige once Paige became an adult. After waiting on a list to be placed in a group home for over 10 years, Paige was instead placed in a long-term nursing care home. Paige was not alone in this placement; between 2008-2012 in Ontario, over 5000 people with developmental disabilities under the age of 65 were admitted to long-term care homes. While long-term care is designed for people who require 24/7 care, most of the residents of long-term care facilities are elderly patients who are not ideal peers for a social and energetic 21-year-old such as Paige. Within the care home, there are few activities available that suit Paige’s needs and interests and, with a caretaker-to-resident
ratio of 1:11, Pam notes that Paige is often left sitting alone in soiled clothing for hours.

The waiting list for a group home in Ontario includes over 12,000 developmentally disabled people. In a group-home setting, Paige would be with peers, engaged in activities, and have a worker-to-resident ratio of 1:3. With such a long list, Nelson notes that Paige may be living with the very sick and the elderly for up to 20 years. However, Paige’s withering, like the withering experienced by many disabled people, is not simply a story about a lack of material resources that would allow for the flourishing of disabled lives. Rather, withering and flourishing are not simply a matter of resources (personal or state) but also invoke forms of futurity that privilege only certain forms of the future for disability and disabled people.

Disabled people who can be easily accommodated, included, enhanced, and capacitated by forms of biocapitalism are much more likely to thrive. Such thriving, however, must still contend with the way in which neoliberal futurity is embedded within the logic of the suffering disabled child who is not expected to grow up. Paige’s withering, then, is related to the enhancement of others; simply capacitating Paige within the context of neoliberal futurity does not address the myriad ways in which disability functions within neoliberal economies.

The ambiguity by which neoliberal futurity mobilizes the suffering disabled child as both a site of no future and a site of enhancement marks disability as contested terrain. Through the examples traced in this article, neoliberal futurity is deployed slightly differently. For Clarence, there can be no future for her disabled children. For Cure SMA, disability produces only a diminishing and dependent child with no future, so it is imperative to invest in a biocapitalist future that can overcome SMA. Jerry’s Kids are presented as having no future, even when confronted with grown-up renegades. The telethon and contemporary fundraising initiatives encourage a hope and investment in processes of enhancement and cure as the only possible future for disability. For Rapp, there is no future for particular disabled children, but there is hope in having another child. The MWF marks disabled children as having no future, but gives the child hope for life today, which is utilized for medical compliance that might prolong the child’s life. With all this focus on the child, it is no wonder that Paige is an unanticipated adult: while there now exists a vaccine to prevent Paige’s condition, it is too late for Paige to receive the future promised by this vaccine (Nelson 2014). Paige is not asking for anything that the telethon, fundraisers, or the MWF can provide—Paige did not die and Paige cannot overcome her condition.

There are compelling reasons to follow Edelman towards negating the Child and the future when thinking through the forms of neoliberal futurity open to disability. Consider, for example, if embracing the withering of Paige opens possibilities that are not readily apparent when advocating for a future, especially a future that is entrenched in cure and enhancement? Is there a way to read Paige as failure, dysfunction, loss, tragedy, or suffering so as to avoid turning her into a form of difference that can be capacitated or simply left to wither? There are good reasons to embrace Paige’s suffering as a way of affirming that the tractable futures available to some disabled adults are not enough. Suffering can be mobilized as a way to highlight the ways in which not all forms of disability can be easily accommodated or adapted by neoliberal forms of capacitation. Using suffering to draw attention to forms of withering that some disabled people experience can be a helpful political strategy, but must be used with caution given the historical mobilization of suffering as a way to mark disabled lives as those not worth living. A politics of suffering is one way to bridge queer and crip theory to highlight the differential ways in which not all disabled people suffer equally, thus exposing the structural forces at play in the capacitation and withering of disabled bodies. Some disabled people are capacitated in ways that are counterproductive to radically refiguring the world, whereas others
are debilitated through violent processes that should not be celebrated. There is no one way to experience suffering, nor can we reduce or trivialize particular instances of suffering. Although it is not possible to entirely escape the frame in which disability-related suffering has been historically shaped and mobilized to render lives as not worth living, shared social experiences of suffering can push us to think more critically about the ways in which suffering is mobilized and to whose benefit.

However, as this article has shown, disability cannot operate in a full negation of the figure of the Child or unequivocally embrace “no future,” as disability is always already embedded in the production of the future as a future of technological and medical advances—a future to be found through the saving grace of biocapitalism. The future is accessible, happy, hopeful, and inclusive, even when it is not (Fritsch 2013). Disability, through neoliberal biocapitalist processes of capacitation and withering, participates in the formation of the figure of the Child, and is thus an important site of contestation.

In contrast to Edelman (2004), I am interested in negating reproductive futurism not only to reject the social order that relies on the Child, but rather to invest otherwise in social relations that complicate both the horizon of futurity and that of neoliberal biocapitalism that underlies our current interest in the future. The fight then, is not an anti-social turn away from the future entirely, but a negative turn away from the future that currently forecloses the possibility of other worlds. It is a question of struggling for a better world and demanding a better future, not for our individual selves, or for our children, but as an ethical gesture of being of and within the world. Muñoz notes: “The act of accepting no future is dependent on renouncing politics and various principles of hope that are, by their very nature, relational” (2009, 94). If it is indeed within relations that disability emerges, then that is where the fight is to be had. Negating neoliberal reproductive futurity is thus not simply a question of fucking the child, but rather investing otherwise in social relations that complicate this horizon of futurity.

Works Cited


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