

Entanglements of Disability, Ethnicity, and Relations: Orienting toward Belonging in George Estreich's *The Shape of the Eye*

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In January 2013, an altercation between patrons and staff at a Houston restaurant made national news. The Castillo family, Eric, Kim and their five-year-old son Milo, who has Down syndrome (formerly called Down's syndrome), were having dinner when another family seated nearby asked to be moved. As the second family relocated, the waiter, Michael Garcia, heard a man in the group say, "Special needs children need to be special somewhere else" (qtd. In Estreich, "A Child" n. pag.). To his credit, Garcia confronted this man about his comment and refused to serve him; further, his act of decency (some called it heroism) was heralded by the media. Reflecting upon this incident in an op-ed piece in the *New York Times*, author George Estreich, whose memoir is discussed below, points out that for most people, this is a tidy, feel good story; however, for him, as a father of a daughter with Down syndrome, and for many familiar with socio-political dimensions of disability, it is a reminder of a long troubling history of cultural ambivalence toward disability. Underscoring this point, Estreich suggests this incident would be better understood as part of an ongoing societal "debate carried out in words and

actions," a debate about "who does and doesn't belong ... about who counts as human" (Estreich, "A Child" n. pag.).

Disability, and more specifically Down syndrome, continues to be socially situated as contingent. In this contemporary moment, even as people with disabilities participate more fully in education, employment, and all spheres of public/familial life, disability is simultaneously framed as a "threat," or reductively used as the definitional boundary of "quality" human existence. Disability studies scholar Tanya Titchkosky parses out this cultural ambivalence through two opposing representational approaches. On one side, she exposes and critiques the ways disability continues to "represent ... an end" (82), suggesting that "our interpretive relations ... [transform] *vital* lived-differences or impairments into nothing but ends ... [encouraging people] to imagine disability as a limit without possibility" (83). Disability as "end" becomes socially visible in the Houston man's desire to relocate disability to "somewhere else." It is visible in genetic research and increasingly "standard" prenatal screening for disabling traits; in end of life debates where significant dis-

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abilities often signify (usually to nondisabled people) an end to quality of life, or worse, cost-effectiveness; or an end, in cases of serious illness or chronic pain, to life “worth living”—an end to a desirable future. On the flip side, however, Titchkosky acknowledges the ongoing disability studies commitment to uncovering “intermeshed place[s] where the meaning of the human is made, unmade, and remade” (89). Both sides of this coin must be considered: how Down syndrome has historically been and continues to be situated as an “end,” and multiple ways narrative, in this case memoir, animates disability as possibility—as a tool to unmake and remake collective ideas about bodies, minds, the human.

George Estreich’s (2011) *The Shape of the Eye: Down Syndrome, Family, and the Stories We Inherit* provides a useful map for exploring these competing processes. This memoir details Estreich’s familial journey following the birth and diagnosis of his second daughter, Laura. For a few days, the “shape” of Laura’s eyes point simultaneously in two directions: toward Down syndrome, or through George’s Japanese mother, toward a marker of familial inheritance. Although the diagnosis is soon confirmed, Laura’s disability and her grandmother’s ethnicity, especially in relation to the historical appellation of Down syndrome as “mongoloid idiocy,” interweave and collide in complex ways. In effect, the shape of Laura’s eyes reshapes the members of her family and their relationships to one another. The author’s investment in Laura’s future and his interest in the histories that shape his mother’s response allow him to put future and past into dialogue, but these perspectives remain, to a large extent, at odds. This tension between histories and futures, and the disorientation and reorientation they produce, frames this discussion. From the outset, the competing narratives of disability pull the solid ground out from under George and Theresa Estreich, but their relational investment in their daughter motivates their growing understanding of her diagnosis, and their social labor toward creating a sense of belonging for their daughter. Equally important, the legacies shaped by orientalist histories of “mongolism” reveal not

only layers of insight about the disconnect between Estreich and his mother, but also crucial insights into the persistent cultural contingency of Down syndrome. *The Shape of the Eye* points the way toward a larger cultural engagement with the sticky racialized entanglements haunting contemporary understandings of Down syndrome, which requires a radical reorientation toward disability as a relational phenomenon, not just within families, but in the broader social fabric.

Entering the World Anew

As a parent with no prior experience with disability, Estreich weaves a tale of waking up to what Tobin Siebers calls the “ideology of ability”—a world view Estreich had, up to the point of Laura’s birth, uncritically accepted. According to Siebers, the most radical way to understand the ideology of ability is as the “baseline by which humanness is determined, setting the measure of body and mind that gives or denies human status to individual persons” (317). After Laura’s birth in 2001, George and Theresa Estreich are confronted not only by her diagnosis, but by the ambiguous meanings and tenuous status this news engenders. They are suddenly inundated with explanations, predictions, medical procedures, and disability advocacy pamphlets, and the confluence of information leaves them overwhelmed. Their emotional upheaval becomes especially evident in contrast to the way they had effortlessly welcomed their first daughter—Ellie—5 years earlier. Looking back, Estreich describes their initial feelings:

We were undone by the news for a long time. If Down syndrome were ordinary in the world, if a common-sense view of dignity and personhood and capability prevailed, then perhaps our early days would have been easier. But Down syndrome is not ordinary in the world. (xiii)

The medical diagnosis is compounded by a persistent cultural unwillingness to accept Down syndrome—or other disabilities—as ordinary human variation. Suddenly these parents inhabit

an unknown territory, without adequate language, understanding or support to fall into the expected emotional ease of arrival; they feel somehow barred from an unequivocal celebration of Laura's birth.

In tracing Estreich's narrative reflection of Laura's tenuous place in the world, Sara Ahmed's conceptualization of "orientation" is particularly useful. Drawing upon affect, phenomenology, and queer theory, Ahmed thinks of orientation as a relationship between the objects (and bodies) people orient toward, and how these affective choices shape who they become. Orientation involves following lines, clearing space, and choosing paths. In terms of sexual orientation, a queer line may be one that is unmarked, a path with less history, whereas a heterosexual line is a straight line, one that follows the (expected, normative) family line. Further, the lines individuals choose to follow (or forge) involve "social investment" (17), which will shape and be shaped by relationships. Thus, relational orientation (or reorientation) shapes the present and future:

If orientation is a matter of how we reside, or how we clear space that is familiar, then orientations also take time and require giving up time. Orientations allow us to take up space insofar as they take time. Even when orientations seem to be about which way we are facing in the present, they also point us toward the future. (Ahmed 21)

A queer line, in this framing, could be affiliated, in critical disability studies, with a "crip" line. Like the term "queer," which has been used to upend and expand critical and activist approaches to non-normative sexualities, the term "crip" offers a shorthand in disability studies to evoke the radical, powerful, and dynamic aspects of disability. Robert McRuer posits "crip" as an important "critical term" (41), even when contested, and founds his conceptualization of "crip theory" on the "belief that crip experiences and epistemologies should be central to our efforts to counter neoliberalism and access alternative ways of being" (41–2). Further, in an effort to confront dominant ideas of disability as an "end," McRuer envisions crip theory working to open up new futures, "to welcome the disability to come"

(208). From this critical perspective, a crip line implies a specific orientation *toward* disability. Like a queer child born within a heterosexual familial tradition, a disabled child born into a family with no history of disability forges a new, often unfamiliar line, and family members who invest time, emotion, and labor clearing the ground with this child actively participate in familial and social reorganization.

Before George and Theresa Estreich are able to focus on clearing space for Laura, however, they must navigate competing narratives of Down syndrome. Not only do they realize they are no longer proceeding on an ordinary (or straight) line, in the hospital in the early days after Laura's birth, they are greeted with opposing discourses of disability: celebratory "person first" assertions (parsing the person from the diagnosis), contrasted with objectifying lists of deficiencies. Estreich explains: "In one, she seemed to be a developing child. In the other, she seemed not even human. She was a defect, a tragedy, an abnormality. I did not see how she could be both. It was as if Theresa had given birth to a blur" (xiii). These early days and weeks are notable because they provide a lens into how such competing narratives distort and shape material responses to disability, and in turn, relationships between parents and children. Rosemarie Garland Thomson offers the critical term "misfit" as a useful means for thinking through contextual, material consequences of disability: "*Fitting* and *misfitting* denote an encounter in which two things come together in either harmony or disjunction" (592, emphasis in original). Garland Thomson points out that "fitting" and "misfitting" provide theoretical flexibility for looking at relationships between bodies and environments—between people with disabilities and the social contexts they inhabit.

In this case, social fears, disability advocacy, and medical knowledge interact to transform Laura from celebrated newborn into a marked human/medicalized blur. She becomes a question in need of answers, predictions, and medical procedures. A fitting newborn would be one without diagnosis; parents would need basic instructions

about feeding, safety, and be sent on their way. A “misfitting body,” in this case a baby with a disability diagnosis, becomes a “jarring juxtaposition,” a person somehow “unsuitable” or “inappropriate” (Garland Thomson 593) to the expectations of “health” in the delivery room. At the same time, the hospital, doctors and nurses sustain Laura, and these medical professionals coach her parents on the intricate processes of feeding tubes, heart monitors, and specialized care. Theresa and George Estreich depend upon these people and their newly acquired knowledge to keep Laura alive and well, but they also intuitively resist the medical overlays that threaten to envelop how they and others understand who Laura might become.

This sensation of blurring reflects not only the misfitting qualities of disability, but a sudden consciousness of the invisible, unspoken, privilege Estreich had previously enjoyed as a nondisabled person: “When we fit harmoniously and properly into the world, we forget the truth of contingency because the world sustains us. When we experience misfitting and recognize that disjuncture for its political potential, we expose the relational component and the fragility of fitting” (Garland Thomson 597). In this space of being “undone” by multiple narratives of their new baby, George and Theresa are also experiencing what Sara Ahmed calls “disorientation,” a process of misfitting involving intense affective wounding, where one becomes uncomfortable, no longer at home in one’s world.

Extrapolating from Franz Fanon’s descriptions of colonization, Ahmed sees disorientation as often being dehumanizing; it is the process of being transformed from subject to object, of shattering, of being cut into pieces by—in Fanon’s case, the white gaze—in Estreich’s case, the medical gaze and a newly evident ableist environment. Further, she describes disorientation as a process that disallows some people to be grounded in the ways others are. This parallels Garland Thomson’s idea of misfitting, but Ahmed focuses upon the emotion, the affect of such disjunctive moments. For Estreich, the period following his daughter’s diagnosis is one of cognitive and emo-

tional disorientation, a time where the ground upon which he had always stood becomes unstable, blurry, unknown. But it is this sense of the “ground” itself being disturbed that seems productive for thinking about the in-betweenness of disability and relationships.

According to Ahmed, this process involves “not only bodies becoming objects, but also the disorientation in how objects are gathered to create a ground, or to clear a space on the ground” (160). As she points out, “disorientation slides quickly into social disorientation, as [...] in how things are arranged” (162). In her focus on queer theory, Ahmed refers here specifically to sexuality, but disability disorientation—as it is often a process of objectification—also reveals elements of dominant social arrangements based upon physical, sensory, and cognitive norms. In their disorientation following Laura’s birth, George and Theresa Estreich experience an unsettling of familiar ground, but their disorientation also allows them to see more clearly how things had heretofore been arranged in ways that fit them, and how they may have to rearrange things (their ideas, knowledge, how they parent, how they extend themselves into the world, etc.) to “clear a space on the ground” for Laura.

Much of this reorientation involves learning to trust themselves as experts of sorts, even as they are just beginning to understand the material medical and social realities of their situation. They soon learn after multiple episodes in the hospital, for example, that they can and should make demands—for the best IV nurse to protect Laura from becoming a pincushion, not to overuse the NG tube in feeding, or simply for more information. From a social perspective, they also realize outside the hospital, people respond to Laura—with feeding tube and oxygen tank—as a child in medical crisis: “All the oohing and ahing vanished, and the worried glances and gawking took over. Laura was a marked child” (Estreich 52). But in the midst of these disjunctions, they also begin to discover new pathways of effortless belonging—with friends and family who celebrate Laura without pause or footnote, and notably through a friendship forged in the hospital with another cou-

ple whose son shares Laura's diagnosis (not just Down syndrome but an impending heart surgery). This friendship introduces George and Theresa to disability community—before they would ever name it such—through the simple relief of shared experience and not having to explain.

Reorienting Toward Relation

Engaged in a process of reorientation, Estreich's memoir invites readers to share in a dual process of discovery and practical advocacy. First, his self-reflective narrative of disorientation maps a radical shift in perspective, a sudden (sometimes reluctant) relocation outside the ideology of ability, where he now witnesses the unwritten expectations he had previously accepted as common sense. Second, as a parent memoir, Estreich models a relational narrative driven by a longing to create environments and relationships based on belonging, on fitting, for Laura. As the Estreichs move beyond medically urgent situations—successfully navigating heart surgery, and helping Laura transition from feeding tube to eating on her own—they begin to focus more on communication, social development, and imagining her future. In this process, they realize their labor, as parents, will be to support Laura, and also to reach out to their community to make sure Laura is welcomed in equal measure to other children:

I was beginning to learn what Laura meant in the world. Though I may have begun to accept that difference for myself, I was still learning what it meant to others; and shame, protective worry, and a selfish concern for my own future difficulties blended together in an ongoing reverie, an inner argument whose terms never seemed fully defined. In this disorientation I turned towards the practical...I wanted her to belong, to attend public schools in regular classrooms, to play soccer, to go to birthday parties. We would give her the extra help she needed; we would teach people to see her as a child. (Estreich 53)

While Estreich acknowledges his own struggle with grief, shame, and fear of the future, he quickly realizes most of his apprehension has little to do with Laura, and much to do with the communities she is beginning to inhabit.

Estreich's turn "toward the practical," his turn toward the social, stands in sharp contrast to many parent memoirs featuring children with disabilities. In her research on a number of recently published parent narratives, Alison Piepmeier notes that many authors focus overwhelmingly on their grief, and in the process position their disabled children within a script of ableism; this script "functions to dehumanize the child by identifying the child as a source of unbearable sadness" (5). Piepmeier, herself a mother of a child with a disability, admits to elements of grief as part of parenting, but also stresses it was never the defining emotion: "My point is not ... that the grief is invalid, inaccurate, or hurtful. My point is that many of the memoirs focus so fully and in such great detail on the grief that this is the overriding emotions of the books" (6). Although most memoirs eventually focus on the joy and humanity of the children, such books ultimately undermine their own efforts to re-humanize disability, and leave ableist assumptions about disability—as burdensome, emotionally draining, and tragic—relatively unchallenged and in tact.

Such memoirs also fail to square with current research on parents of disabled children. Gail Heidi Landsman, in a series of in-depth interviews with new mothers of children with disabilities, found that many mothers were more troubled by feeling "called upon to justify [their] continued investment in what is publicly perceived as a defective commodity" (159). From these interviews, mothers expressed grief about external responses to their children, not about their children. For example, some mothers recounted being told by friends and family members not to "waste their whole lives" or "sink all of their time" (qtd. in Landsman 159–60) into the care of disabled children, as if this type of care and nurturing would not be cost-effective. Similar sentiments are expressed by UK parents in an extensive recent collection titled *Families Raising Disabled Children*. Rather than feeling grief about their children, parents, "spoke of the empathy they now had for their own disabled children and other disabled people in terms of the disabling barriers they shared" (McLaughlin et al. 87). Many parents

articulate a new understanding of social injustice, and come to see disability more clearly as a political issue, not an isolated individual or familial source of grief.

Along these lines, Estreich acknowledges his own doubt, fear, and disequilibrium, but refuses to locate the origin of these emotions in the body of his child. Resonant with critical disability studies scholarship, the author situates the dilemmas of Laura's future not only in her ongoing development and potential, but in the myriad social contexts—some welcoming and inclusive, others resistant, possibly even hostile—she will encounter as she grows. As Estreich stresses, one of the most persistent and troubling social assumptions he and Theresa encounter centers upon Laura's very existence, "the question, whether spoken or not, was always: Did you test?...[and the] implication was clear: this all could have been avoided" (8). Like many parents, they are righteously indignant, but rejecting ableist assumptions is only part of the process of clearing new ground. Part of their labor, as parents, becomes directed toward reshaping beliefs that would box Laura into simplistic categories such as *tragedy* or *avoidable mistake*. To that end, the writing of the memoir itself is a labor of transforming social arrangements. By inviting readers to enter into relationship with Laura Estreich, her family, and their imaginings of her future possibilities, the author offers a deeper connection to the multi-dimensional humanity of individuals often reductively understood as diagnoses.

Grounded in an ethic of affiliation and investment, Estreich's memoir enacts what Aimee Carillo Rowe calls a "politics of relation." She sees relationship and belonging as crucial to subject formation:

A politics of relation is... to tip the concept of subjectivity away from individualism and in the direction of the inclination toward the other so that being is constituted not first through the atomized self, but through its own longings to be with... to a sense of "self" that is radically inclined toward others, toward the communities to which we belong, with whom we long to be, and to whom we feel accountable. (27)

Carillo Rowe sees experiences of belonging as changing, multiple, and sometimes competing.

Relational belonging is locational, emotional, and political. For Estreich, parenting Laura profoundly changes his subjectivity and his sense of belonging. Carillo Rowe's idea of "longing to" belong seems especially compelling, because building alliances demands a deep affective affinity, a valuing and orienting toward another which ultimately compels individuals to forge alternative social pathways.

Like most caring parents, mothers and fathers of disabled children feel deeply accountable and "radically inclined" toward their children. Part of all parental labor comes in the form of socializing children and preparing them to contribute to and participate in their local and wider communities. However, as philosopher Eva Feder Kittay, herself a mother of a daughter with cognitive disabilities, has argued, the labor for parents of disabled children involves not only care and socialization of the child, but entails labor to "help shape a world that will accept [the child]" (398). For Kittay, who has pioneered critical discussions in philosophy about the field's dehumanizing deployment of cognitive disability, her intellectual labor is motivated by her affinity and alliance with her daughter:

My daughter, Sessa, will never walk the halls of academe, but when what happens within these halls has the potential to affect her, then I as an academic have an obligation to socialize academe to accept my daughter... [I]t may be far-fetched to call this "care," but it is part and parcel of that labor of love that we do as parents, especially parents of disabled children. (398)

As Kittay points out, people with disabilities, parents and allies, are often engaged in labor that remains largely unnoticed or invisible. For parents, such labor may entail going to IEP meetings, smoothing social transitions in school, managing support services, working with para-professionals, not to mention negotiating public spaces where people may be kind, curious, solicitous, or downright rude. On top of such everyday labor, many parents engage in more public and collective labor such as challenging prejudicial attitudes by educating teachers, professionals and peers; working toward more equitable policies; and removing barriers that threaten to impede the opportunities of their children and other disabled people.

Parents like Kittay and Estreich invite readers into intimate familial moments, but more importantly, into a spaces that are purposefully inclusive. These parents are engaged in a process of reimagining the world—of reworlding imaginations. As Estreich explains: “To be a parent is to keep a story, to nurture another’s identity through time. Because of this, a list [diagnostic list] is at best insufficient to the experience, at worst inimical. A list has no room for story: It is a world without individuals, a world without verbs” (162). Estreich is motivated by a desire to open the future for his daughter, to build upon the disability rights, education policies, and supports that have been put in place, and to promote a cultural imaginary that sees his daughter as a complex individual—sweet, yes, but also stubborn and determined—and as integral in her world, as someone who belongs. Aimee Carillo Rowe further argues that this sense of relation requires people to shift their subjective focus beyond the autonomous self: “Belonging, then, helps us imagine identity, subjectivity, and a sense of self that [...] strives to connect. [...] This inclination toward another involves seeing others to whom we belong as inseparable, not separate, from us” (35). From this perspective, belonging is a collective struggle, a collective enterprise. As Estreich maps out the labor he willingly takes on for his daughter, he also demonstrates that her belonging will require the labor of many, many others. He sees story as a crucial pathway toward such collective rearranging; through story, relationships emerge, and the heavy lines separating people potentially begin to blur and fade.

Entanglements of Disability, Ethnicity, and Family

Engendering this sense of belonging is a difficult, uneven, and messy project, and even among family members, disability, ethnicity, history, and memory form a complicated web of entanglements. This section turns to the competing narratives of (dis)orientation within Estreich’s memoir

—his complicated relatedness to disability and his mother’s conflicted relationship, through her ethnic heritage and immigrant history, to Laura’s diagnosis. Estreich’s title, *The Shape of the Eye*, evokes multiple meanings. Almond-shaped eyes are, of course, a visible marker of Down syndrome, but also a trait of many Asian people, and historically, this was the singular feature John Langdon Down focused upon when he coined his infamously racist/ableist classification: “mongoloid idiocy.” Estreich and his mother’s conflicting ideas and affective responses to Laura’s diagnosis reverberate throughout the memoir. This ongoing familial friction around ethnicity and disability might be best understood through a lens of “entanglement.” Rey Chow, who theorizes entanglement through art and fiction to reconsider broader relations of power, captivity, and government, considers this process from two angles: first, the more “familiar connotation of being emotionally tied to a person or an object, from whom or from which one cannot extricate oneself”; and against this common sense understanding lies an “epistemic sense of entanglement” which entails a rearrangement “in the organization of knowledge caused by unprecedented adjacency and comparability” (11). This forced rearrangement of knowledge begins with Laura’s birth. Suddenly, the historical and seemingly distant existence of the moniker “mongoloid idiocy” intermixes with Estreich’s ethnic history, and he and his mother become entangled in competing interpretations that cannot be separated from one another—or easily reconciled.

When Estreich tells his mother about Laura’s diagnosis, he discusses the confusion over the shape of Laura’s eyes, and mentions the condition’s historical name, “mongolism.” His mother grows silent on the phone, then slowly repeats the term: “‘Mongolism,’ she said. ‘Why would you say that?’” (28). What he doesn’t anticipate is that his mother hears the term as an accusation—that she is somehow to *blame*. In response to the conversation, his mother frantically searches the internet for a *defense* and begins quoting online inaccuracies, one being that Down syndrome always comes from the mother. This misinformation, and reverse accusation, only infuriates

Estreich, and leads to more miscommunication. In a subsequent conversation, after more research, his mother informs him that babies with Down syndrome used to be put up for adoption, a historical fact he misinterprets as a suggestion, which angers him further. Later, he realizes his mother was only trying to point out that times had changed for the better—that Laura would have opportunities today that would have been unavailable in previous generations.

Estreich rightly narrates his mother's difficulties with Laura's diagnosis as ableist, and challenges her ongoing unwillingness to accept the diagnosis. During Laura's first year, for example, Estreich's mother wants to interpret Laura's ability to learn, her language acquisition, her intelligence, as evidence the diagnosis is false—rather than as evidence of the falsity of negative stereotypes. Estreich tries to understand her perspective, but her rejection of Down syndrome resonates, in his mind, simply as a rejection of Laura:

She says, hopefully: "Did you see, did you see how careful she was when she came to that step?"

"Yes," I tell her. "Yes, I saw."

"And she is so *alert!*"

A pause.

"Maybe," she says, "maybe the doctors were wrong. Maybe she doesn't have Down syndrome."

I say: "She took the step carefully because Theresa spent weeks and weeks teaching her how. And she does have Down syndrome. She does."

She says: "Her eyes are so *bright!*"

Pause.

Then fervently: "There could be a *genius* in there!" (137-8)

Such comments rightly frustrate Estreich, and expose his mother's inability to see Laura, disability, *and* intelligence as compatible. Even as she witnesses Laura's accomplishments, playfulness, and unique humanity, instead of using her personal experience with her granddaughter to rescript the meaning of Down syndrome, she endeavors to rescript Laura.

At the same time, however, Estreich resists engaging with his mother's sense of disorientation with the term "mongolism," and the distinct way

this shapes her reaction to Laura. As a Japanese immigrant who moved to America with George's father after World War II, she inhabits this term in a way her son seems unable to understand. To her, the term "mongolism" is profoundly dehumanizing. Not only is this an historic and racialized term, but she hears it as a personal accusation, a signifier of some kind of genetic taint that she has passed down to her granddaughter. Certainly, her reaction is a form of internalized ableism, but her rejection and defense against Down syndrome could also be read as a form (albeit misdirected) of alliance. In rejecting the diagnosis, she is trying to shield Laura from a racialized stigma that has wounded her in ways her son doesn't understand, and this ethnic pride drives her familial impulse to resist the label.

In many ways, Estreich's mother responds out of a sense of shame (or a rejection of being shamed) deeply attached to her Japanese ethnic identity and the history she inhabits. He, in turn, responds defensively to shield Laura from any form of shaming related to disability, especially from her grandmother. The tension between mother and son, at times, seems insurmountable:

I wondered whether we would be estranged permanently. It seemed at least possible: Laura's arrival had catalyzed a reaction difficult to reverse. It seemed sometimes what was left between us was pulled tight and thin as DNA itself—a narrow cable, stretched across the continent—and Laura's arrival had stretched that cable to its tensile limits. At what point, I wondered, do the bonds break? (147)

This conflict between George Estreich and his mother point to larger tensions between competing forces of ethnicity, nationality, disability and inherited histories.

A growing number of disability studies scholars have recently been addressing the intersecting and enduring material effects of racism and ableism. Anna Stubblefield, for example, argues compellingly that the persistent disproportionate number of students of color in special education is tied to antiquated and racially motivated IQ tests: "The problem is that the concept of intellect that we continue to employ in the United States was constructed by white elites to provide a scientific justification for racism" (301). Stubblefield traces

the deeply intertwined history of race and disability from a decidedly eugenic past to contemporary practices that still embrace problematic ideas about the predictive power of intellectual exams. Ultimately, her work underscores the need to be continually mindful about the myriad ways race and disability have been intertwined historically and continue to buttress and shape each other. In addition, she stresses that poor people and people of color “suffer” disability in ways white middle and upper class people often avoid.

In contrast to many poor, undereducated, parents who may be ill-equipped to navigate disability services and Individualized Education Program (IEP) meetings, or working parents who simply don't have the time or resources to advocate successfully for their disabled children, George and Theresa Estreich are highly educated and comfortably middle class. At the time of writing, George had given up his job as a composition teacher to write at home while parenting full-time. Theresa, the main breadwinner while Ellie and Laura are young, is a professor who successfully earns tenure at Oregon State University. Ethnicity, in George's (and Laura's) case, often registers as white, and is never mentioned as a factor of notice or oppression—outside of George's hearing a few racialized epithets as a child. By the time he had reached the age of nineteen, Estreich confesses that he didn't look very Japanese, and his ethnicity, beyond being proud of his inheritance, had faded to the background in a white dominated social landscape. With the arrival of Laura, however, his ethnicity and questions of family flood into his conscious thoughts:

What did family mean now? What would our family be like, and what did that have to do with the family I came from? Being “half” white and “half” Japanese: what did that mean, exactly? [...] I live it from the inside out; beneath the unconscious dailyness of identity was a pride in my heritage. I did not live by halves. And yet, in the appearance of my second daughter, these categories meant something else. (188)

Estreich's engagement with his Japanese heritage, definition of family, and the history of Down syndrome suggests a shift from intersectionality toward (dis)orientations and entanglements. As Rey Chow points out, these realms of

“sticky, sentimental entanglements [can be] both blockages and throughways” (11). With honesty and a growing politics of relation with his daughter, Estreich traces his own sticky path, and in the process, reorients himself and his readers, not just toward Laura, but toward new cultural perspectives about Down syndrome.

As Estreich battles with his mother, he also admits to struggling with his own ableist perceptions: “In the beginning... it was easy to think that my mom was in denial and I was facing facts. It's probably more accurate to say that we were going through a similar process, but that I was more fluent at disguising it” (243). As he tries to uncover and articulate what Laura—and her diagnosis—are coming to mean within their family and community, he turns to the writings of John Langdon Down. One of the key elements Estreich pulls from these papers is the way Langdon Down described “his Mongoloid idiots” (Estreich 194) by detailing the traits of one boy. Down justified this approach because, to his mind, the children resembled one another so closely they could stand in for one another. Estreich argues, rightly, that with this gesture Down “personifies the syndrome [...] blurring child and diagnosis into a single, representative type” (194). Rhetorically treating these individuals as interchangeable, Down established those with *his* diagnosis as kin to each other, not to their families. Further, Down solidified existing racial hierarchies by establishing kinship through an orientalist, ethnic classification. As Estreich points out, “When Down chose to see his ‘idiots’ in terms of race, he made use of the way race was understood” (195).

It is well known that John Langdon Down was following the racialized scientific beliefs of his time, but these entanglements of ethnicity and disability continue to haunt Down syndrome. The name Langdon Down introduced in the 1870s wasn't formally changed in medical and scientific circles until the 1960s. Although many researchers had long discussed the unfortunate ethnic connotations in the term “mongolism,” it wasn't until French geneticist Jérôme Lejeune discovered the genetic basis by identifying “the presence of a third copy of a chromosome (later, in 1960, to be

named the twenty-first chromosome)” (Wright 123). In 1961, the British medical journal, *The Lancet*, following upon Lejeune’s newly confirmed research, suggested five new names, including Trisomy 21 and three options including Down’s name. The editor recommended the arguably more conservative alternative, Down’s Syndrome, and over that decade, most English speaking scientists and doctors adopted this name, although “Mongolism” continued to be use popularly well into the 1980s. Notably, French speaking scientists adopted the more genetically descriptive name, Trisomy 21—or more accurately “trisomie vingt-et-un” (Wright 115–121).

The politics of naming is not a neutral process; “mongolism,” and Down’s surname continue to figure and haunt the diagnosis, and to touch the families of and individuals with Trisomy 21 in complex ways. Down’s original ethnic classification enacted racism and ableism through a commonplace gesture of Western imperialism. Sarah Ahmed offers a provocative reading of Edward Said’s conceptualization of orientalism. Like Said, she highlights the way European construction of the Orient positioned Occident as subject, Orient as object. Further, though, Ahmed complicates this process of othering: “Rather than othering being simply a form of negation, it can also be described *as a form of extension*” (115). In other words, it allows some people to extend their reach, to extend what they can “have” and “do” (116). As Westerners such as John Langdon Down learned to conceptualize the Orient as something distant and foreign, this allowed them to bring elements of the Orient—in Down’s case, “Mongolians”—home and domesticate them, and in this way, to extend the reach of the West.

This gesture of imperialism, of orientalism, haunts Estreich’s narrative and his family’s early understanding of Laura.

Our lives seemed an echo chamber from the past: a nineteenth-century mistake was audible in our twenty-first-century lives. [...] Family, ethnicity, inheritance, disability, belonging. [...] Everything in Down’s paper seemed familiar and unfamiliar at once. But that was how his “idiots” seemed to him, and, in a very different way, that was how Laura first seemed to us. She had arrived in our family, but she was radically unfamiliar: *A child first*. (188, italics in original)

Down’s gesture also reflected an undisguised paternalism, where he was benevolent father, and his charges, “his idiots,” perpetual children. But as Estreich points out, Down’s paternalism also constructed those with the diagnosis as a family of their own—they were not kin to their biological parents, and to Down’s way of thinking, “they did not even seem to belong to their parents’ *race* (Estreich 185, italics in original). Further, even with contemporary progressive attempts to see the child first, children diagnosed with Trisomy 21 also “inherit *Down* as their second surname” (Estreich 198). As Estreich stresses, this surname “accompanies the family name, on medical charts, insurance forms, IFSPs” (198). Current debates over naming focus on the apostrophe, and families who reject Down’s possession, his gesture of paternity, are also, to Estreich’s mind, acting to “reclaim a child from diagnosis. To say that there are many proper names, and not only one” (198).

Conclusion

Sara Ahmed links inheritance to proximities, orientations and family paths. She pays attention to the ways family lines can be constricting, and how those seen as threatening the family line may simply be breaking with expected “straight” lines. At the same time, family relations are fluid, dynamic, and responsive to new relationships: “we inherit proximities (and hence orientations) as our point of entry into a familial space, as ‘a part’ of a new generation. Such an inheritance in turn generates ‘likeness’” (123). Inheritance, in other words, is shaped by proximities, by unfolding relationships. Within the context of Estreich’s memoir, the meanings of inheritance—of almond shaped eyes, of a second surname—are initially shaped by ambivalence, by lists of deficiencies, but are ultimately reshaped by Laura, by her individuality, her proximity. Inheritance, in this sense, comes from the past, but is reoriented from parent to child and child to parent. In his orientation toward

Laura, *toward* disability, Estreich unmakes ideas of Down syndrome as an “end,” and clears new ground to remake the future.

Parents who offer intimate narratives of familial relationships, especially with their disabled children, provide readers with an intimate understanding of some of the complexities, joys, and rich humanity of disability. *A child first*. Estreich plays with this phrase throughout the memoir. “A child first” (188). It functions as a reminder from advocates to remember the humanity, the child, the person. But this phrase never captures the complexity, the possibility, that he finds in his own daughter. Further, it fails to adequately address the ongoing contingent nature of Down syndrome and disability more broadly. As Estreich’s narrative, and as the incident at the Houston restaurant demonstrate, racialized conceptualizations of kinship and disability continue to haunt contemporary misconceptions of people with Down syndrome as limited, as childlike, and separate—as part of the same family—a special family “somewhere else.” This separateness is routinely reflected in cultural discourse *supporting* people with disabilities. Returning briefly to the dinner incident with the Castillo family, the waiter, Michael Garcia, explained his personal anger toward the ousted patron with this question: “How could you say that about a beautiful five-year-old angel?” Ms. Castillo complicated this portrait of her son, stressing that he likes “to give hugs,” but that he is also, sometimes “obnoxious [...] like any other [five]-year-old” (qtd. in Estreich, “A Child”). To be fair, Garcia knows the Castillos as regular customers, and perhaps he thinks of Milo as angelic, but too often such syrupy sweet words attempt to cover over disability rather than simply allowing it to be integral or ordinary. Such comments run the danger of repositioning disabled people as “better”—not as belonging.

Estreich’s memoir, engaged in a process of disorientation and reorientation, reveals much about the sticky entanglements of disability—those that have acted powerfully upon his family, but that also reach out and touch our collective histories

and futures. The futures, the very existences, of people with Down syndrome will be shaped by competing narratives of genetic research, prenatal screening, educational strategies, cost-analyses, access to community services, and disability rights. As Estreich’s memoir demonstrates, discussions of any of these issues will be more useful and just if people with Down syndrome participate, and if they are seen by nondisabled people as real people with rich, complicated, and interconnected lives. As Estreich argues, story is an essential element in this relational equation: “If our technologies are to benefit people with Down syndrome, then their lives need to become more real to us. Science can illuminate part of that reality, and technology can affect it. But only story can convey it” (208).

Works Cited

- Ahmed, Sara. *Queer Phenomenology*. New York: Routledge, 2010. Print.
- Chow, Rey. *Entanglements, or Transmedial Thinking about Capture*. Durham: Duke UP, 2012. Print.
- Estreich, George. “A Child With Down Syndrome Keeps His Place at the Table.” Editorial. *New York Times* 26 Jan 2013. Web. 18 Feb 2013.
- . *The Shape of the Eye: Down Syndrome, Family and the Stories We Inherit*. Dallas: Southern Methodist UP, 2011. Print.
- Garland Thomson, Rosemarie. “Misfits: A Feminist Materialist Disability Concept.” *Hypatia* 26.3 (2011): 591–609. JSTOR. Web. 21 October 2011.
- Kittay, Eva Feder. “The Personal Is Philosophical Is Political: A Philosopher and Mother of a Cognitively Disabled Person Sends Notes from the Battlefield.” *Cognitive Disability and its Challenge to Moral Philosophy*. Eds. Eva Feder Kittay and Licia Carlson. Malden, MA: Wiley-Blackwell, 2010. 393–413. Print.
- Landsman, Gail Heidi. *Reconstructing Motherhood and Disability in the Age of “Perfect” Babies*. New York: Routledge, 2009. Print.
- McLaughlin, Janice, Dan Goodley, Emma Clavering, and Pamela Fisher. *Families Raising Disabled Children: Enabling Care and Social Justice*. New York: Palgrave Macmillan, 2008. Print.
- McRuer, Robert. *Crip Theory: Cultural Signs of Queerness and Disability*. New York: New York UP, 2006. Print.
- Piepmeyer, Alison. “Saints, Sages, and Victims: Endorsement of and Resistance to Cultural Stereotypes in Memoirs by Parents of Children with Disabilities.” *Disability Studies Quarterly* 32.1 (2012). Web. 12 Sep. 2012.
- Rowe, Aimee Carillo. *Power Lines: On the Subject of Feminist Alliance*. Durham: Duke UP, 2008. Print.
- Siebers, Tobin. “Disability and the Theory of Complex Embodiment—For Identity Politics in a New Register.” *The Disability Studies*

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- Reader*, 3rd ed. Ed. Lennard J. Davis. New York: Routledge, 2010. 316–35. Print.
- Stubblefield, Anna. “The Entanglement of Race and Cognitive Dis/Ability.” *Cognitive Disability and its Challenge to Moral Philosophy*. Eds. Eva Feder Kittay and Licia Carlson. Malden, MA: Wiley-Blackwell, 2010. 293–313. Print.
- Titchkosky, Tanya. “The Ends of the Body as Pedagogic Possibility.” *Review of Education, Pedagogy, and Cultural Studies* 34.3–4 (2012): 82–93. JSTOR. Web. 8 Feb. 2013.
- Wright, David. *Downs: The History of a Disability*. Oxford: Oxford UP, 2011. Print.