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ORIGINAL PAPER

Who Counts? Care, Disability, and the Questionnaire in Jesse Ball's *Census*

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Abstract

In the *Biopolitics of Disability*, David Mitchell and Sharon Snyder (2015) assert that disabled people are subjected to endless health and government questionnaires that harvest their data in exchange for better care. As disability advocates such as the National Disability Rights Network (2021) have demonstrated, these questionnaires—like the 2020 census—are highly flawed because disabled populations are not asked to shape the questions that will determine government funding and access to medical care. Although data collection is a source of contemporary literary and scholarly interest, few works explore this in the context of disability. However, Jesse Ball's 2018 novel *Census* examines questionnaires, specifically the census, and illuminates how narratives of disability are warped by the faulty data these objects collect. I argue that the protagonist, a dying father whose son has Down syndrome and requires full-time care, uses what Jack Halberstam calls "queer failure" to create a more equitable census that *will* make possible the kinds of care disabled populations deserve. Rather than create a perfect, objective questionnaire, the father skews the questions and data to center disability in the story of America, as he moves away from recording everyone's experiences and instead highlights the lives of disabled people, their caretakers, and their systems of care (doctors, neighbors, etc.). I suggest that this "failed" census reveals those networks and systems of interdependency that scholars like Judith Butler (2020) and advocates such as Leah Lakshmi Piepzna-Samarasinha (2018) posit would radically change how care is approached, thus rendering the census as an object of care.

Keywords Disability · Data · Inclusion · Biopolitics · Algorithms · Care

In his foreword to *Census*, Jesse Ball (2018) explains that he wrote the novel in honor of his late brother Abram, who had Down syndrome. Ball clarifies, "I thought I must write a book that helps people to see what it is like to know and love a Down syndrome boy or girl. It is not like what you would expect, and it is not like it is ordinarily portrayed and explained" (2018, x). *Census* follows a dying father, referred to only as "the doctor," and his unnamed son with Down syndrome, as they move through several towns conducting

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the census. Most of Ball's literary work, which has been critically understudied, explores issues of disability, inclusion, and caretaking. For instance, in *The Way Through Doors* (2009), a young inspector named Selah Morse tends to a cognitively impaired woman after he witnesses her brutal accident. Meanwhile, in *A Cure for Suicide* (Ball, 2015), a futuristic society grapples with a population plagued by despair. In *Census*, the doctor and his son encounter people with various physical and cognitive disabilities while undertaking their duties, and both men listen to each citizen's story. What makes *Census* so significant in its portrayal of disability and care is how Ball illuminates these issues in the context of data collection. More specifically, the doctor and his son create a skewed, and therefore deeply flawed, census when they decide to privilege counting those with disabilities and/or the families, medical providers, and guardians who care for them above simply counting everyone.

This essay adds to the growing body of work on care by exploring the ties between data collection and care taking, an interdisciplinary subject that scholarship has yet to fully consider. Scholarly examinations of care typically center on race, gender, and labor, which is unsurprising given that this work is often performed invisibly by female minorities and/or framed in terms of martyrdom and selflessness (Walters 2017). The labor of caring for people also tends to be seen as an "individual chore," whether that is done by subjugated workers or family members, because there are so few support systems in place within the U.S. for collective care (Lakshmi Piepzna-Samarasinha 2018, 33). By focusing on care, my essay also builds on the work of feminist scholars, who argue that this lens that illuminates all those whose "bodies are not being cared for" adequately within the American health care system (Novotny and Opel 2019). *Census* explores the lack of support systems available to disabled populations at length; throughout the novel, individuals or families are expected to shoulder the work of caring for them alone. In fact, the protagonist admits that for most of his son's life, he and his wife cared for him without the help of others, with the exception of a neighbor who will watch over his son once the father dies (Ball 2018, 8). Across his journeys, the doctor's conversations with others reveal the complicated, maladaptive forms of care that disabled people endure because of an ineffective social safety net. Significantly, Ball never frames disability as a burden, nor does *Census* situate caretaking as burdensome. Instead, the novel exposes how various systemic issues, like violence, prejudice, neglect, and greed prevent individuals from receiving adequate medical care. It also elucidates a quandary: although masses of personal data are collected by various institutions (like the U.S. Census Bureau), there is little evidence that any of this information has created a more equitable system for disabled populations and their caretakers. The "flawed" census that the doctor and his son create draws attention to this irony and imagines a reality where the census questionnaire could lead to actual improvements in the social safety net.

By examining *Census* in the context of data collection, care, and disability, this paper illuminates a significant interdisciplinary gap in contemporary literary explorations of "datafication," a term that José van Dijck (2017) uses to describe the "transform[ation of] all things under the sun into a data format" (11). Many twenty-first century novels explore the perils of datafication, such as Joanna Kavenna's (2020) *Zed* and Nicola Barker's (2017) *H(A)PPY,* both of which present worrying, dystopian futures wherein human experience is translated into constant streams of data that allow authoritarian governments to "know" and surveil their people. Literary interest in datafication is understandable because contemporary writers are "confronting and making sense of" how our data is read and interpreted by governing agencies (Kern 2020, 83). As Olivia Banner (2018) notes, over the last few years, people have become hyper-aware of how algorithms shape online experiences and collect data on online presences (45). Yet, as Banner observes, despite the growing interest and concern with how our data is collected, interpreted, and narrativized, there is a dearth of scholarship on how "big data" shapes narratives about disabled populations, and she attributes this gap to the belief that the Internet would increase accessibility and foster inclusion for disabled users, rather than inhibit moves towards better inclusivity (2018). Scholarship on literary depictions of data rarely broaches discussions of disability. While *Census* does not explicitly engage with these topics in digital spaces, it is nevertheless preoccupied with how governing agencies use the data we collect on disabled populations.[1] Throughout the novel, Ball explores what it means to shape the process of data collection, especially when this information will be interpreted by the federal government. The protagonist is keenly aware of how he and his disabled son shape the process of data gathering as door-to-door census takers, and he realizes that the information they collect will affect how the nation understands disability and care.

While *Census* is concerned with how governing agencies collect data on disabled people, it also interrogates how the health care industry interprets data gathered on this same population, hence its depiction of various physicians and health care settings. Data collection is a vital component of the current health care system and occurs at several levels (payment, medical history, medical trials, etc.). Improving the ways that data is collected helps patients receive better care; thus, the medical community tries to gather data objectively and accurately (Kwok et al. 2022). As digital scholars have demonstrated though, the algorithms and AI programs used to interpret illness often flatten or erase disability and reflect ableist biases (Whitaker et al. 2019, 3). Rendering the human body into data is a heavily flawed and metaphorical process because information about bodies is simplified and translated into digital data points (Zuboff 2019). I argue that *Census* demystifies this metaphorical rendering by making the process concrete. At various moments, the novel draws attention to how people's lives are converted into data. For instance, the doctor is given an "ink-gun" to make a physical mark on citizens' ribs that proves their information was collected (Ball 2018, 79). While the protagonist notes that most census takers make this mark carelessly, and thereby hurt those who receive it, he opts to use "a mechanical tattoo needle […] and fresh black ink," so the process is gentle and safe (2018, 79). In other words, he turns a cruel process into a caring one, using materials that will comfort the person enduring the procedure. He also includes how disabled people's bodies look and move in his data; the objects that maimed them; and the "things" that bring them comfort. In doing so, he highlights the heterogeneous nature of disability, something that data collecting algorithms often fail to capture (Whitaker 2019; Nakamura 2019; Wald 2021).

Failing the right way

As disability scholars have demonstrated, the way that data on American disabled populations is collected and interpreted is applied through an ableist framework. While the myriad problems with how data on disabled populations is collected is not the primary focus of this article, elucidating how collected data on these populations often silences and/or distorts them gives context to Ball's exploration of care in *Census*. Furthermore, for the sake of this essay, I largely focus on how demographic information about disabled populations is interpreted by governing agencies, primarily because *Census* examines these issues within the contexts of visibility and inclusion. Americans live in a time wherein the increased collection of data concerning disability, disease, risk, and mortality "assist[s] nations in an improved knowledge of all bodies with respect to the further universalizing norms of functionality, appearance, and capacity" (Mitchell and Snyder 2015, 10). Disabled people, in particular, are subjected to having their personal information gathered constantly, for medical, work, and demographic purposes (Mitchell and Snyder 2015).

Although we would expect that governing agencies would use this wealth of demographic information on disability to give ample insight into the needs and realities of disabled Americans, as many disability networks, disability scholars, and A.I. scholars have observed, federal agencies typically fail to gather this information accurately. In a 2021 report on representation and federal data collection, the National Disability Rights Network (NDRN) notes that while the federal government tried to improve outreach to disabled people during the 2020 census, this data contained numerous gaps that misrepresented disabled populations (8).[2] As the NDRN notes, the Census Bureau labels disabled populations "hard to count," so they are undercounted (2021, 34). This occurs, in part, because disabled people are rarely asked to help shape the methods by which the federal government collects data (2021). Since the government does not necessarily rely on the census to collect specific information on disability, it instead must gather this information via various surveys. As a result, issues arise, partially because the nature of data collection is such that the unique needs of people with disabilities can be lost amidst the need to categorize large groups of people at once (Wald 2021). The impacts of inaccurate data on disabled populations are wide reaching, affecting everything from education services to criminal justice (NDRN 2021).

Due to delicate nature of collecting data, and the myriad issues that arise when it is collected poorly, many contemporary novels about this subject depict error, failure, and inaccuracy as potentialities to be feared.[3] Throughout *Census*, however, the doctor sees the value of disordering the systems that gather demographical data. He skews this data by flooding the system with stories of disability and caretaking that will eventually be reported back to the bureau. Rather than position his decision to do this as potentially damaging, the novel suggests that by purposefully misrepresenting the population, the doctor centers disability and caretaking in the story of America. As such, I argue that he employs "queer failure" to expose how chronic misrepresentation of disabled populations helps us create a skewed narrative of national success and inclusivity (Halberstam 2011). Queer failure "dismantles the logics of success" and suggests that "[u]nder certain circumstances failing […] offer[s] more creative, more cooperative, more surprising ways of being in the world" (Halberstam 2011, 2–3). Importantly, queer failure disrupts notions of normativity.

Given the disruptive and subversive nature of queer failure, and its critique of normativity, many disability scholars have long identified it as a useful way to "crip" systems and institutions. Courtney J. Andree (2018) argues that queer failure "offer[s] productive frameworks for understanding the forms of rupture, anti-development, and negativity that so often accompany disability narratives" (27). In this way, error is not something to be avoided but to be embraced because they "reveal the truths they displace" and function as "sites of revelation" (Davidson 2022, 3). Banner touches on this issue when she explains that although scholars and activists often question what they can do to crip digital databases and spaces, there are better opportunities for subversion by having activists and disabled populations simply refuse to participate in "improving" digital databases (2018, 54). These lines of queer and crip refusal inform why the doctor in *Census* eventually realizes that the best way to improve how data is collected on disabled populations is to simply not improve the system at all and instead to undermine it. By creating a deeply flawed algorithm, the doctor illuminates the need to consider who writes the systems by which data is collected and demonstrates that they change for the better when we develop more inclusive ways of writing them.

Collecting "knowledge"

In *Census*, the kinds of data that must be collected, and the knowledge that emerges from this data, are both left vague. Readers only know that the doctor must ascertain "what is special about [each] individual" and that this "data must pass through [him] back to the offices of the census in such a way that what is most particular, most special about the nation, and indeed of all nations" (Ball 2018, 34). Initially, the parameters of the census appear thorough. The doctor must interview those living between the towns of "A" to "Z," and this breadth suggests that the census is exhaustive. He also knows that he will "call out of the people [he] meets that which is indeed most peculiar to each" and that the methods by which the census taker does this is left to each individual, with the understanding that the data must be collected objectively (2018, 34). However, the doctor becomes skeptical of the process when he actually sees how census data is recorded. Showing the doctor a "huge cabinet of leather-bound volumes" that "went the length of the hallway" and contains all the data past census takers gathered, the protagonist's supervisor weeps because "[i]t was too much for him to even come near the effort of so many lives," and he both assures the doctor that the census is "the real work" of the nation and emphasizes a "need for" consensus (2018, 48). Since the doctor will be gathering so much data, he must learn to "aggregate" it around consensus points before the information is sent to his supervisor (2018, 34). The doctor realizes, however, that he will not be so much collecting data for the census, as much as he is collecting knowledge about and proof of *consensus*. Ideally, the collected data will flatten the experiences of those he interviews into a single, unified narrative of national success and exceptionalism so that it can fit in one of these books. The knowledge being pursued is merely the affirmation that Americans are collectively succeeding.

The lived experiences of the doctor and his son run counter to this narrative of blissful consensus that the Census Bureau seeks to uphold. The doctor is dying of an unspecific heart-related disease, and he is very near the end of his life. Much of the novel concerns his fears for his son, as he requires full-time care, which worries the protagonist given how people typically react to his son's disability. Although the son seems unaware of how people mistreat him, the doctor reveals that whenever he and his late wife took his son places, people would "heckle" their son, "stare," or "as[k] some hidden question, some completely unnecessary question" intended to ostracize him (Ball 2018, 41). As a result of these experiences, when the supervisor reveals his love for consensus, the doctor instead finds "[t]he need for consensus […] the most disgusting and pathetic aspect of our human world" (2018, 48). He has witnessed first-hand how privileging normativity inspires many to alienate anything outside these norms. In a sense, he is being asked to manipulate the data he gathers on marginalized populations he counts. The citizens he must interview, like his son, have experienced complicated hardships outside of their control, so their lives inherently challenge the homogenous narrative the doctor is being asked to reaffirm.

For disabled populations, there is an especial fear about how their experiences are eclipsed so that the U.S. can uphold mythic notions of success and inclusivity. The personal data collected by agencies on disabled populations is often distorted, precisely because it threatens the narratives about American exceptionality (Mitchell and Snyder

2015). Collected data tends to be used in two ways, "as […either] evidence of the triumph of American exceptionalism, and/or as threats to the productive mandates of market capitalism" (Mitchell and Snyder 2015, 11). Said differently, when agencies collect data on disabled populations, they use it to celebrate the nation's advancements in "inclusion," which bolsters the ethos of the nation, or they use it to denigrate those who cannot work and to suggest they are dragging down the nation. Viewing disabled populations in these limited contexts reinforces what Robert McRuer (2006) calls the "system of compulsory able-bodiedness—the experience of the able-bodied need for an agreed-on common ground" (8). This "agreed-upon common ground," its own kind of dangerous and illusory consensus, demands that all bodies fall in line with normative views of able-bodiedness. People like the doctor and his son, who both require constant help and care, fall outside these norms. Aware of this, when the doctor sees his son after he agrees to gather data for the census, he observes that his son's census "began at birth" because people began to "measure" him (Ball 2018, 4). Unable to fit into the "consensus" that the census upholds and champions, the son endures a separate form of measuring that invites people to see him as unworthy and unvaluable.

Perhaps it is no surprise then that the novel explores the many ways by which people try to measure and understand each other. At various moments in the novel, the doctor reads a book called *Geometries of the Dive*, a nonfiction work on cormorants written by Lotta Werter under the pseudonym Gerhard Mutter. The book contains "a series of illustrations, hand-drawn, sometimes employing traced photographs" created "to scale" of cormorants and their environments (Ball 2018, 45). Throughout the book, Mutter argues that for people to feel like they know something, they wrongly assume that they must try to master and diminish it. She writes, "We who are masters of nothing […] cannot understand what it is like to be naturally, a master—to obtain a sovereignty that does not grasp, but extends in somehow palpable lines from the edges of every feather, from the point of the beak, the globes of the eyes" (2018, 46). Here, Mutter argues that humans are not carefully observing cormorants, because if they were, they would not try to fit the birds' behavior into preconceived categories forged by unequal power dynamics. These dynamics arise because the humans observe the birds "from above, from nowhere, from simplicity" (Haraway 1988, 589).[4] Such a view, though it frames itself as objective, is necessarily limiting, and the doctor echoes this when he realizes that "the census is in some way an observation," one that is inflected by those who conduct it because the information is gathered in person via conversation rather than anonymously (Ball 2018, 14).

Mutter's insight helps the doctor delineate between acknowledging diversity/disability and making it visible as opposed to simply naming/identifying it. At various moments in the novel, the doctor worries about the systemic need to merely identify or name difference. For instance, when the protagonist interviews a kind doctor who cares for him when he faints during an interview, the kind doctor complains that "[t]he naming of things has never been systematic"; as such, he desired a "an entire new scheme of naming—the renaming not just of every part of the body, but also of all illnesses, so that the entire matter of the human form and its sickness could be easily understood" (Ball 2018, 121). By creating such a system, the kind doctor believes the body would be definitively knowable. The protagonist, however, understands that knowledge is never definitive and is in a sense always flawed, always held back by our "present understanding" of something (2018, 121). Furthermore, as the protagonist notes later, naming/identifying things often inhibits our ability to "tel[l] one thing apart from another […because] the knowing of these names is then spoken of as being identical to the excellence of discriminating between the parts […] The wondrousness of felt experience resides in the discrimination, not in the name" (2018, 146-147). In other words, being able to name populations, parts, or people gives us little insight into what makes each one special. Instead, we must understand the unique, heterogenous capabilities of each person and/or population.

This differentiation between name and experience explains the doctor's methods of collecting data on disabled populations. Notably, he does not categorize those he counts by their specific disability. Even though he encounters and counts disabled people along his census route, he does not label them as partially paralyzed, traumatized victims of environmental catastrophe, and/or physically impaired, even though they technically fit these descriptions. Instead, he captures the narrative of disability by recording their lived experiences. While this method may seem simplistic, such a conceptualization of defining disability coincides with how disability activists want it framed: not as simply a diagnosis or label, but rather, as a unique form of knowledge known only by those who are disabled. Tobin Siebers (2019) when he argues that "[d]isability is a body of knowledge" because disabled populations hold a different understanding of a "society as a consequence of embodying it" (42). As Siebers observes, however, disabled populations are rarely asked to "share [this] knowledge," even though creating opportunities to relay it would "plac[e] a premium on the disabled subject as a knowledge producer" (2019, 42; 47). By shifting our understanding of the kinds of knowledge disabled populations can offer, we in turn gain more nuanced insight into our society. The protagonist understands acutely how disability is a "body of knowledge," often overlooked by society, given the care both he and his son requires. But to transform the census into a record of such knowledge, he must first dismantle the beliefs about what the census should be.

What it means to care

While *Census* never outwardly suggests that American society lacks strong networks of care for its people, readers intuit this absence in various contexts, the first of which is how the census itself is conducted. First, census takers cannot expect any kind of support or safety while they journey through the various towns counting their populations. Many times, the doctor draws attention to the physical journey he takes—how he and his son must traverse open fields, roads, and neighborhoods to gather data, but they are not allowed to carry weapons to protect themselves (Ball 2018, 72). As the doctor explains, census takers are considered expendable; their bodies are merely resources the government uses to obtain more data on its people (2018, 72). Those gathering data for the census must think of themselves not as individuals but as conduits for the census, there to "amass, amass" information and not influence the data they find. Initially, the doctor agrees and even believes that he should collect his data objectively (2018, 102). He reaffirms to the reader that census takers are trained to be wary of how subjectivity can lead to bias, noting: "[t]he fact that we mar our impressions, mar the scenes we enter by even our presence alone—it is something census takers carefully, gently even, pretend not to know" (2018, 3).

In many ways, the rules surrounding the census reflect many misnomers about data collection and objectivity. As Dominik Balazka and Dario Rodighiero (2020) observe, people assume that data speaks for itself and is collected neutrally; however, this assumption (which does not account for error, bias, or subjectivity) is erroneous because "data collecting algorithms are constantly changing […] and [are] naturally selective human artifacts." These scholars add that big data cannot possibly capture every experience of every person (Balazka and Rodighiero 2020). Indeed, despite the understanding that census takers must be objective, even the U.S. Census Bureau as Ball imagines it does not try to "count" everyone. For instance, when the doctor comes across a pair of runaways early on, he reveals that amongst census takers, "[t]here was the question of whether runaways should be counted. Some would say not. I took a different view" (Ball 2018, 36). The lack of guidance about who should be counted, alongside the assumption that runaways are not real citizens, means that the census is inherently flawed.

Rather than work to correct such flaws, the doctor leans into them. As the novel progresses, the stories that the doctor relays about his fellow citizens coalesce around the same subjects: disability and care. Although he is supposed to capture what makes the nation great, he instead highlights the lived experiences of those with disabilities and those who care for them. At times, the stories illuminate what it feels like to love someone who society disregards. For instance, while in the town of "D," a woman informs the doctor that he is "cursed" by having a son with Down syndrome (Ball 2018, 54). In another town, the doctor allows his son to ask the questions, but the man they are counting only wants to look at the doctor and respond to him instead (2018). Thus, to an extent, the census becomes proof of both society's continued discomfort around disability and the obstacles that the disabled face. He contrasts these stories of exclusion with one of inclusion when he describes a woman he meets in the town of "B" who has suffered some terrible injury to her arm (2018). The doctor notes that after an afternoon filled with joyful discussion and laughter, she embraces him, and his son "grasped her withered arm" with affection when she reaches out to hold each of their hands (2018, 16). The doctor highlights how "natural" it is for the son to touch her arm lovingly instead of recoiling at it, indicating that his son's instinctual behavior to be caring and inclusive is exceptional, not because he is disabled, but because he is compassionate (2018, 16).

In other moments in the text, the doctor's interactions with others highlight the deeply complicated roles that caretakers assume, especially in the absence of a strong social safety net. This is especially evident in the doctor's recollections of the town "H," a place where most able-bodied men and women must work in a dangerous rope factory to provide for their families (Ball 2018). Before entering this town, the doctor "abdicate[s]" the "typical work of the census" and decides instead to "misbehave" and to determine what stories ought to be told (2018, 131). Thus, he concerns himself both with the number of gruesome injuries and deaths that the workers suffer at the factory and with the doctor who tends to these workers (2018). What he discovers dismantles the mythic American exceptionalism that he has been asked to find via his interviews. The town features a prolific graveyard so full that it takes the doctor and his son nearly an hour to walk through it (2018). While speaking to the factory's doctor, the protagonist is told that in the absence of real government oversight or any true corporate responsibility, the desperate townspeople maimed their children by cutting off their thumbs so their children can avoid the factory work: "He [the factory's doctor] touched the bump of one absent thumb with his forefinger. You see, I will never make rope. Never" (2018, 136). In the town of "H," then, disability is not something to be feared or maligned; instead, disabling another person is an act of love and care, disturbing as that may be to outsiders. In fact, when the protagonist asks the factory doctor if his maimed hands make the job harder, the doctor's terse assurance that it does not reveals that he understands his privilege: his disabled hands will lengthen and improve the quality of his life; he will live even as others continue to fill the cemetery (2018). Because of this privilege, he sees caretaking as a form of ethical obligation, one that inspires him to "work without pay" so he may help those who, like all his family members, died while working in that same factory (2018, 134). Furthermore, the factory doctor corrects the protagonist when the latter asks if the workers are simply hurt because they failed to adhere to safety guidelines. The former man assures the protagonist that "the rope machines cannot be operated safely" because they were not designed with safety in mind (2018, 136). The workers then are almost fated to be brutally hurt or killed because of the equipment, suggesting that, at best, the town of "H" is filled with people who require constant care because of corporate neglect. By "misbehaving" and choosing to illuminate this story, the protagonist simultaneously highlights the terrible lengths that some must go to so they may care for and protect others and the pain that workers endure so others may profit. Furthermore, his attention to material aspects of the town—the sheer number of graves, the doctor's mutilated thumbs, and the dangerous conditions within the rope factory—does more than simply record disability, it shows the physical tolls that the town endures because there is no oversight.

Most of the stories that the doctor collects come from the townspeople he meets, but when he decides to count a toy as a citizen, he casts light on how American society fails to care for its people by refusing to address cyclical violence. While in the town of "L," the doctor meets a little boy who asks him to include Henry, his doll. The protagonist agrees to do this, noting that to "add Henry to the data would not cause too much harm," and he asks the boy's father, a policeman, to tell him Henry's story (Ball 2018, 167). The policeman's story reveals wide failures in American society, noting he found the doll at the scene of a crime where a woman "committed suicide and [took] her two children with her" (2018, 168). Although the policeman does not extrapolate further, readers realize that everyone in the household has suffered from a lack of care: the mother did not receive the treatment she needed, nor were the children kept safe from violence. Henry thus becomes a proxy for the kinds of care the family members should have received. The policeman recalls seeing Henry "lying prone beneath the bed of one of the dead children," prompting him to think that "Henry needed a home" (2018, 168). In reality, the dead child that the policeman found needed a safe and caring home but was denied this. Henry goes in his/her place, being cared for in a home where he is so loved that the boy wants him included in the narrative of the United States. The doctor's belief that Henry, despite not being a person and therefore outside the purview of the census, will serve as an important "consensus point" is accurate (2018, 167). Henry is a reminder both of the lack of support and care that some Americans experience and of the violence that many Americans refuse to address, and his toy "body" stands in the place of the child who was killed because of this neglect.

Using the census to build a care collective

Even though the doctor knows that he is not supposed to receive or demand care as a census taker, he nevertheless needs it at various moments in the text. While in the town of "I," the protagonist becomes weak and is taken in by a "kindly old couple" (Ball 2018, 142). The couple encourages the son to help them run their store and they treat him so well that the doctor becomes concerned about "why they were so kind" (2018, 142). Once he recovers, the woman shares the story of her late daughter's life, as her daughter also had Down syndrome. The woman feels compelled to share that her daughter "liked to sew things, although it was not easy for her, and she liked surprising people" (Ball 2018, 143). By recounting the story of the couple's deceased daughter, the doctor creates an error in the data: dead citizens are not supposed to be counted in the census. Her story, however, is a meaningful contribution to the narrative that the doctor must create because it acknowledges the power of visibility. She praises the doctor, noting, "for people to see you two traveling together, and to see how your son can live and take joy—I think you cannot know the good you do" (2018, 143). Understanding the need for disabled populations to be seen and valued, she adds, "we didn't keep our daughter in our home out of sight. In the mornings, she would go out and wander the town, and everyone knew her. There is a kind of understanding that can grow in a place, and then everyone, every last person can be a sort of protector for them" (2018, 143). While she acknowledges that most disabled people are not treated with respect, she explains that the town of "I" is an aberration because "here, something grew" once the townspeople saw and valued her daughter (2018, 143). Even as she acknowledges that some people remained "[c]ruel to her" in the cities outside of "I," those within the town who saw her regularly felt changed by her presence (2018, 143). Unlike the doctor's isolating experience of caretaking alone with his wife, the old woman describes a "care collective," or a form of communal care taking that can be "a site of pleasure […and] joy" (Piepzna-Samarasinha, 2018, 46). In "I," caretaking is performed equitably and lovingly.

The shift that the kindly old woman describes—the transformation of the townspeople from being either ignorant about or ambivalent to disability—suggests that interdependence forms when people can recognize the bonds that hold communities and one another together. As Judith Butler (2020) notes, "interdependency […] implies social equality: each is dependent, or formed and sustained in relations of depending upon, and being depended upon" (16). In other words, when we recognize interdependency, we move from hyper-individualism to relationality. According to Butler, when we turn away from hyper-individualism, we better recognize how every person deserves equitable living circumstances (2020). Notably, when the kind woman describes how her daughter's presence in the store transforms the town, she asserts that her daughter "confer[ed] on others […] a kind of momentary vocation, […] a real gift" (Ball 2018, 143). Framing the daughter's care as a "gift" to the town rather than a burden subverts the narrative of disability as antithetical to national success. The daughter fosters interdependence amongst others because people in "I" who otherwise may not feel socially connected to one another are yoked through their mutual decision to come together and protect her. The woman feels compelled to tell the doctor about her daughter, not only because she loved her, but because the woman acknowledges that "so few people in these later days […] care about the kind of person [people with Down syndrome] are" (2018, 143). As her story demonstrates, to create the conditions conducive to caring for people like her daughter, knowledge about those with Down syndrome must be collected and shared with everyone across the country. The data the doctor gathers about the daughter undermines conceptions about disability by showing how independent and important her daughter was, even though she had to be cared for by her parents.

Although he never acknowledges this explicitly, the doctor also creates a care collective around his son, one that spans across all the towns that he visits. This is significant given that the doctor's health dwindles over the story and ends with him acknowledging that he is going to die, thus he must send his son back on the train alone (Ball 2018, 110). When the doctor is asked early on in his travels what will become of his son if they are very far away from their hometown when he dies, the protagonist explains that his son will ride the train back and that he has always been comforted by the notion that "[t]here is always someone who has it in themselves to help him [his son]," should his son struggle with navigating the train back home (2018, 110). As the protagonist dies and the novel draws to a close, he imagines his son being shown around by a kindly conductor who will "become fond of [his] son" and help him feel safe on the train (2018, 240). This is a marked difference in the doctor's belief in mankind from the beginning of the novel. Whereas he begins the novel somewhat cynical and distrustful based on the experiences he has endured watching his son being bullied, he now recognizes the potential for people to join together in caring communities. Moving through the towns and recording the experiences of those there, watching strangers play with, admire, or talk to his son changes not just the perception of those in the towns themselves, who perhaps abandon some of their prejudice or ignorance about disability, but also the mind of the doctor. He recognizes the bonds of interdependency he has forged by introducing his son to many different people who now know and love him. As the novel closes, the doctor asserts that his son is in fact "the true census" because his "eyes have seen all" and his "heart has felt all," and he will be the one to convey the data they collected to everyone who meets him in the future (2018, 241). In some way then, his son has co-written the census narrative, and although the doctor has transmitted some of the census data via forms, the most thorough form of the census exists within his son's mind and body. If, as demonstrated earlier, disabled voices are rarely invited to shape the questionnaires that endlessly collect their data, the protagonist of *Census* purposefully subverts this. His own experience as a terminally ill man, alongside his son's thoughts and feelings about the townspeople they meet, shape the census and challenge the narrative of the nation they were meant to uphold.

Ultimately, the novel prompts readers to question what kinds of stories we want to tell about the nation with the information we gather on its people. The actual U.S. Census Bureau (2023) does not explicitly tie the census questionnaire to care work. However, it does acknowledge that the census "tells us who we are and where we are going as a nation" (U.S. Census Bureau 2023). In other words, the census plays a vital role in the narrating the story of the United States. To an extent, *Census* tells a story of a deeply flawed America, one plagued by endless violence against family members and workers, and full of prejudice and neglect: this is certainly the story that the doctor experiences as he watches his son's life unfold. But the novel also illuminates the potential for something more, a way for communities to form around disabled people so that their care is not shouldered by solitary individuals. The story that the doctor writes is at once revealing and heartbreaking, but it is also just as much optimistic and joyous. *Census* ultimately suggests that if it is possible for the census to truly represent the nation, then those collecting data must fully capture its polyphonic nature.

Author contribution I am the sole author of this essay.

Declarations

Competing interests There are no competing interests.

Endnotes

[1] Frédéric Kaplan and Isabella di Lenardo (2017) qualify that "[b]ig data is big when it is in a state of continuous open-ended expansion." Said differently, people often conflate "big data" with digital algorithms and online stores of data; however, if the data collected is in "perpetual extension," then we can consider it big data (Kaplan and di Lenardo 2017). The protagonist in Census explains that the census is done every few years and is amassed in hardback volumes held in the Census Office (Ball 2018). Because this project is by its very nature open-ended, and collects data in wide swaths of people, I find that Census is an interrogation of big data.

[2] For the history of how the Census Bureau has altered questions on the questionnaire to better assess disabled populations, refer to their website: https://www.census.gov/topics/health/disability/guidance/data-collection-acs.html.

[3] In Joanna Kavenna's Zed, a glitch in an algorithm leads to the death of an innocent man, who is falsely accused by a predictive crime algorithm (2020). Nicola Barker's H(A)PPY explores the

violent repercussions a character endures when she accidentally bypasses the algorithm meant to keep everyone the same level of "happy" (2017).

[4] While Ball never overtly mentions Donna Haraway by name here, Mutter's name may be a tongue-and-cheek reference to her essay "Situated Knowledges" (1988), given both the overt reference to Haraway's "mother/matter/mutter" paradigm (596) and Geometries of the Dive's preoccupation with observation, knowledge, and bodies.

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