International Journal of Communication 20(2026), 435–455 1932–8036/20260005

Toward Disability Data Justice: A Critical Discussion of Disability and Big Data Discourses

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The terms of inclusion/exclusion of disability in big data are ultimately connected to the kinds of discourses that inform disability in society. Since the rise of big data as a phenomenon, disability's absence in it, especially in the data formations that underpin artificial intelligence and machine learning, is notable. However, nowhere are data sets and disability more connected than in disability censuses—underscored by the efforts of the Washington Group on Disability Statistics to create internationally comparable disability statistics. The divergence is clear: Why is international cooperation to incorporate disability in data collection gaining speed, yet disability bias and discrimination still pervade traditional and new kinds of data? In this article, we bring critical disability studies in conversation with critical data studies to consider how disability is valued in big data. We argue the importance of adopting a disability data justice approach to crip the normative structures that underpin disability data and to ensure that disabled people control and govern the data collected about them.

Keywords: disability, inclusion, big data, census, data justice

In the Singapore population census of 2020, disability statistics were collected for the first time in the country's relatively short modern history. As the national newspaper *The Straits Times* reports, the census found that 2.5% of Singapore's resident population had difficulty performing a basic activity of living measured across six domains: seeing, hearing, mobility, self-care, communication, and remembering (Tan, 2021). The media report highlights this as a significant milestone, even as some interviewees called for more granularity and details in the data collected, for instance, by collecting data specific to each disability type in the Singapore context, specifically physical, sensorial, intellectual, and developmental disabilities. Despite this, interviewees—disability sector organizations and academics alike—highlighted the data as "useful" and "positive," given that the information might facilitate the development of better services for disabled people (Tan, 2021).

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Date submitted: 2024-09-26

When it comes to disability, national censuses and how disability is defined in them have been at the center of improving the inclusiveness, quality, and appropriateness of data collection on disability. This is partly driven by the passing of the United Nations Convention on the Rights of Persons with Disabilities (hereafter "the Convention"), which saw the mainstreaming of the rights of disabled people. Crucially, the Convention highlights the need for disability data, noting in Article 31 that state parties should "collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention" (United Nations General Assembly, 2007, Article 31). What comes to be understood as appropriate information of disability collected, especially in censuses, however, depends on normative contexts that influence what counts as disability data, as we shall discuss. More broadly, the work of creating standardized disability statistics predates the Convention. Specifically, the Washington Group on Disability Statistics was initiated in 2001 to foster international cooperation to produce and create comparable disability statistics globally (Washington Group on Disability Statistics, 2020). As Madans (2016) writes, the influence of the Washington Group cannot be understated, with a long list of state parties, international organizations, and nongovernment organizations partaking in it. Notably, its formation contributed to consistent data collection of disability in some national censuses.

We open this article with this vignette about the population census in Singapore as an entryway to an issue central to our discussion in this article—how disability comes to be captured within data, what might be left out, and the discourses that circulate around it. The Singapore case is significant because it highlights the importance of collecting disability data in big data sets such as censuses; however, calls for more granularity in data collected in the Singapore case also highlight how some data are perceived as being left out, even as the census marked a significant milestone.

In this article, we bring together critical disability studies in conversation with critical data studies to consider the kinds of values informing both the presence and absence of disability in big data. Our theoretical approach is informed by a disability data justice approach, one that, in the spirit of data justice (Dencik, 2025), critiques data ableism and aims to examine and dismantle the structures that exclude disabled people. As Gorman et al. (2024) highlight, disability data justice begins with a critique of all forms of data ableism and prioritizes the democratization of data and digital literacy from the perspective of diverse disability communities. In their discussion on artificial intelligence (AI), Bennett and Keyes (2020) note how a focus on disability justice allows us to "critically examine the overarching social structures we are participating in, upholding and creating anew with our work" (p. 4). More crucially, disability data justice also interrogates the ways technoableism—the belief that disability is undesirable and must be eliminated, often through the use of technology—may be present in data (Shew, 2023). A disability data justice perspective thus allows for greater clarity on how disability comes to be captured (and even produced) within data, the implications this has, and what opportunities it allows for the future.

Beyond critique of the kinds of structures and discourses data are embedded within, a disability data justice approach also calls for disabled people to be in charge of data, from how information is collected to how it is interpreted and utilized. Cripping data is one way to enact disability data justice, where the normative structures around disability are constantly interrogated and examined. As Blanchard, Blanchard, and Shew (2025) explain, "A cripped data science has to be one that not only puts crips in charge, but allows crips to subvert regimes of data that serve to constrict, incarcerate, and police disabled identities"

https://doi.org/10.65476/192t5w27

(p. 371). To apply a disability data justice framework to the question of disability in big data sets such as the census, we ask the following questions in our analysis:

RQ1: What influences the collection of disability data in large-scale data sets such as a census, and how do these logics shape other, newer kinds of data sets prevalent in an algorithmic and social media era?

RQ2: Which kinds of normative stances and considerations inform data about disability, especially as they are deployed in the census?

RQ3: How can progressive stances about disability, influenced by the Convention and evident in the shifts in censuses, inform and eliminate bias in problematic uses of big data?

We begin with a discussion of big data's relationship with disability and how populations come to be accounted for in censuses. We follow by discussing the normative contexts surrounding disability data collection in Singapore and Australia censuses. We end with concluding remarks on the possibility of achieving disability data justice.

Big Data and Disability: A Complex Relationship

"Big data" firmed up in the early 2010s as a key term for grappling with the volume, pervasiveness, and potential uses of the extraordinary amount of data associated with and generated by an expanding role of digital technologies widely used in daily life. One of its key attributes was that this flood of data outstripped the capacity of existing database, computational, scientific, and social scientific protocols and systems to deal with and leverage it (Kitchin, 2014). Big data has the potential to address social issues when deployed accordingly, but also create new problems, especially in terms of extending state and corporate power and eroding individual liberties and freedoms. As boyd and Crawford (2012) note, in an era of big data powered by tech, researchers need to "critically interrogate this phenomenon, its assumptions, and its biases" (p. 665).

More important are the questions of what data do and what implications this has for understanding disability within contemporary societies. For Koopman (2019), data are inscribed by a terrain of power and politics that mediates what people can or cannot do (p. 8). As Bowker and Star (1999) highlight, the ways data are classified are a result of human choices and have consequences for the objects that are sorted. For example, sorting populations by race across government policies was a way to enact segregation in apartheid South Africa (Bowker & Star, 1999); similarly, data have long been a way to sort people based on quite contingent fabrications of disability (Soldatic & Fitts, 2020). As Soldatic and Fitts (2020) note in their analysis, criterion that determines eligibility into disability welfare systems can change depending on government policies. Individuals are, as Koopman (2019) asserts, "cyborgs who extend into our data" (p. 8).

With the advent of big data associated with pervasive digital technologies, the visibilities of disability within data is an important topic that deserves deeper consideration, especially in relation to questions of disability data justice. In discourses of big data and disability, a recurrent theme is the potential

https://doi.org/10.65476/192t5w27

of data to better account for and promote justice for disabled communities. An early instance of this from a disability rights perspective is user- and activist-driven mapping of barriers and inaccessibility of built environments. These efforts show the potentialities when disabled users take advantage of digital technologies and data. This was highlighted in the collaborative work of Catalan artist Antoni Abad in his megafone.net project (https://megafone.net/). From 2004 to 2015, Abad worked with disability activists and communities in places such as Barcelona, Montreal, and Sydney to use mobile phones and the Internet to gather data to create a map of accessibility in public places (Goggin, 2014), something that might be seen as an example of what Milan and van der Velden (2016) term "alternative epistemologies of data activism" (p. 57). In relation to improving large data sets on disability, big data, as well as data mining, analytics, and so on, has been seen as a major opportunity (Bizzego et al., 2020), especially in relation to areas such as health (McDermott & Turk, 2015).

It took a while before disability emerged as an acknowledged area in discussions on discrimination and bias in big data (still not very evident, even in treatments that aim to be systematic; see Favaretto, De Clercq, & Elger, 2019). However, there is, as Whittaker et al. (2019) note in a landmark report, a pronounced disability bias within AI. Notably, AI treats people with disability (and other marginalized groups) as outliers in the data sets it relies on (Deitz, 2023). Within disability and technology studies, there is a longstanding critique of the disability biases within technologies such as AI, algorithms, and automated decision making, all of which rely on large data sets (Nakamura, 2019). Moreover, with the recent advent of and interest in generative AI models, which rely on large data sets to create new data, scholars have similarly highlighted how disability is invisibilized and not fully represented (Gillespie, 2024).

It is not just disability biases in data sets that are the problem; rather, how data sets are interpreted, utilized, and analyzed by algorithms can also create problems for disability. In the United States, scholars have highlighted how the Americans with Disabilities Act affords little protection for disabled people when it comes to the use of big data and algorithms in health insurance industries (Hoffman, 2017) as well as in hiring and employment (King & Mrkonich, 2016). In their study of Robodebt, an automated debt assessment and recovery system implemented by the Australian Department of Social Security between 2015 and 2019, which wrongly and unlawfully demanded repayment of benefits from 600,000 recipients, Goggin and Soldatic (2022) note this has had an oversized negative impact on disabled people. This is further perpetuated in challenging these decisions (see also Park & Humphry, 2019).

Smart city technologies, which have increasingly been pointed to as opportunities for social and economic change in the Asia-Pacific region (Zhuang & Goggin, 2024), are also exemplary of the problematic relationship between big data and disability. Deitz, Lobben, and Alferez (2021) point out that "in the smart city, infrastructure is not only the pipes and roads, but also the data that undergirds the life of the city" (p. 2). As Reuter explains (2020), smart cities aim to "transform the city to the benefit of their inhabitants and governments" (p. 4), with a pervasive reliance on using real-time data (Kitchin, 2018). Concerning disability, smart cities can be problematic, given how data sets can often exclude disabled populations. Discussing the Toronto smart city project, Treviranus (2018) highlights that the main issue is how data points that deviate from the norm, such as those originating from disabled people, are eliminated from data sets. The smart city is thus an ableist one in its reliance on both the collection and analysis of normative data.

https://doi.org/10.65476/192t5w27

In this way, disability is a very interesting case in relation to big data and its discourses. The different kinds of big data offer the potential to make visible and track various things associated with disability and impairment. For example, the growth of sensing technologies—and their incorporation into Internet, social media, mobile, and Internet of Things systems, devices, and objects—generates new kinds of data (e.g., on movement and mobility) that offer new ways to represent, detail, respond to, and intervene in aspects of the lives of people with disabilities, including by disabled people themselves (Nectoux, Magee, & Soldatic, 2023) experimenting from the context of their own data cultures.

When deployed appropriately, big data has the potential to support disabled people's emancipation in society. Examples abound: Projects such as Opensidewalks, Project Sidewalk, and AccessMap deploy crowdsourced data to locate accessible pathways geared toward users' preferences and reimagine the physical city (Zhuang & Goggin, 2025). AI tools such as Seeing AI, Signapse, and Voiceitt—which deploy machine learning with large data sets to provide key services such as identifying objects, providing automated text-to-sign translation, and performing speech recognition—have been central to the transformation of the everyday lives of disabled people. Nevertheless, as Crawford (2021) argues in the *Atlas of AI*, even as data are central to the workings of such AI technologies, the training data sets they rely on not only embed racialized, gendered, and ableist bias but the genealogies and practices surrounding data sets also raise important ethical issues, and questions of exploitation and extraction abound.

As Banner (2018) cautions, we are often unaware of the extractive logics of big data, especially those that are seemingly benevolent. Crucially, Banner notes how Facebook's automatic alt text technology is ultimately a form of technology—image-based mining—that can be lucrative for Facebook and can also lend itself to the automation of labor and lead to the loss of jobs (Banner, 2018). Seemingly unrelated digital trails, as Gooding (2024) highlights, can be used to generate and create inferred data, which can lead to surveillance and policing of disabled populations, especially when existing data protection laws are insufficient. Disability, and its generative knowledge and labor, then comes to be embroiled within the extractive logics of big tech capitalism (Wu, 2023).

However, as disability activists and scholars have noted from the outset, disability also brings into play issues of what kinds of data are gathered from which technologies; what kinds of users, networks, environments, and relationships; framed by what kinds of assumptions and concepts (especially about economies of visibilities); and for what purposes. A shorthand for one set of issues here is "outliers," as Welles (2014) noted in her version of "the case for making Big Data small":

> Women, minorities and statistical outliers have historically been omitted from the scientific record, with problematic consequences. Big Data affords the opportunity to remedy those omissions. However, to do so, Big Data researchers must choose to examine very small subsets of otherwise large datasets. (p. 1)

Disability's place and function in big data discourses dovetail uneasily into the international pursuit of better, fairer, more accurate population data. Amid the proliferation of big data in technologies, censuses, given their longer histories, create precedence for the datafication of both humans and their activities (Burgess, Albury, McCosker, & Wilken, 2022, p. 36); in the case of disability, this is highly significant for

https://doi.org/10.65476/192t5w27

understanding the discourses and logics embedded in data. Many data on disability are administrative data, rather than census data, gathered for a wide range of reasons, especially because of welfare, health, carceral, institutional, and other rationales for classifying, gathering, and counting people with disabilities (e.g., Prince, 2016). Thus, there is major tension: Why is global cooperation to incorporate disability in a wide range of data gathered by governments, statistical agencies, institutions, corporations, businesses, and market and academic research gaining pace, while at the same time, as the recent focus on AI and associated computational and data technologies underscores, questions of disability representation, inclusion, and bias come up in new ways in big data sets and the analytics, conceptual frameworks, and methods used to make sense of them (Whittaker et al., 2019)? Yes, it is often the case that the actors, their purposes, infrastructures, and assemblages involved in the creation of big data sets are not centered in or explicitly contemplating disability data gathering, as others involved in the global cooperation, such as the Washington Group, doubtlessly are; nonetheless, the gulf between the two areas is striking.

Accounting for Disability in Populations

The disability census—as a privileged mode of gathering large-scale data—offers a different orientation where disability is highly visible and present, as we have pointed out. Beginning from the 1970s, but gaining pace at the turn of the millennium, disability rights increasingly took center stage in the international arena, driving a heated debate on disability definitions and classification (Bickenbach, 2012). An offshoot of this has been the advent of international consensus around measuring disability. As the United Nations (2001) highlights, this has led to renewed attention in measuring disability statistics with the aim of improving services and the inclusion of disabled people. The problem is that disability is defined differently across national contexts, and there is thus a need to make uniform the ways disability is measured in the population to produce internationally comparable statistics (United Nations, 2001). The formation of the Washington Group on Disability Statistics in 2001 emerged out of these concerns. The group coalesced many years (since the 1980s) of effort by international agencies, such as the United Nations, to effect action on disability data collection (Loeb, 2013).

The advent of the Convention on the Rights of Persons with Disabilities in 2006 lent impetus to these efforts through the mainstreaming and centering of disability rights (Lawson, 2006). Beyond the Convention, regional initiatives such as the Incheon Strategy, led by UN agencies in the Asia-Pacific region, have also established key indicators for disability data collection and reporting (Cao & Murphy, 2022). These indicators include monitoring the ratification and implementation of the Convention in the Asia-Pacific region, but also specific issues including accessibility, poverty reduction, and employment (UNESCAP, 2020). More specifically, enumerating disability plays critical roles in monitoring if and how state parties are meeting the obligations of the Convention to enable those with disabilities to participate equally in society (Madans, Loeb, & Altman, 2011). At the same time, disability data collection in the census can create infrastructures that allow for big data analytics and mining (Aragona & Zindato, 2016). Despite this broader shift and focus on disability data, there remain wide disparities in how disability data are collected and how disability is defined, as our case studies show.

In relation to the Convention, Madans (2016) and Loeb (2013) are optimistic that the introduction of the Washington Short Set on Disability Statistics has the potential to improve monitoring and achieve the

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objectives of the Convention. More importantly, as Mont, Madans, Weeks, and Ullmann (2022) note, implementing the Washington Short Set allows for international harmonizing and comparison of disability data, yet the 2023 report of the Disability Data Initiative highlights that only 70 of a total of 188 countries surveyed (37.2%) deployed the Washington Group Short Set of questions (Hanass-Hancock et al., 2023). Crucially, this gap in data collection has implications on the abilities of state parties and governments to spotlight inequalities and address service gaps pertaining to disability (Leonard Cheshire, 2024).

As history shows, the ways in which disability is captured within population censuses can also be imbued with problematic logics. For instance, Trent (2016) notes the U.S. census did not count those labeled as "idiots" or "insane" until 1840. While the 1840 Federal Census measured disability, its findings were used to justify inequalities and the marginalization of populations on the basis of disability, namely, free Black Americans (Baynton, 2001). As Rose (2017) argues, the deployment of these categories in the American censuses ultimately serves as a punitive means to rehabilitate particular groups of the American population to achieve productivity goals. Counting and labeling people (in particular, with disability), and the terms with which this is undertaken—as these cases remind us—can, at the least, be extremely problematic.

As Hacking (2013) points out in his classic text, the enumeration of people and particular populations reflects "a particular medico-forensic-political language of individual and social control" (p. 164), what he calls "making up people." In other words, the kinds of statistics collected within censuses offer a window into understanding how classification reflects societal shifts in understanding about deviance and marginalization, among other issues. Noting the emergent focus on enumerating disabled populations from the 19th century, scholars have emphasized how this trend signifies a form of moral statistics aimed at improving the health of the population (Wisselgren & Vikström, 2023). Discussing the Swedish population census and its enumeration from the 1860s to 1930s, Wisselgren and Vikström (2023) note that the state increasingly became more concerned with accuracy, amid a growing concern that disability in the population was detrimental to the nation's health. Given the evolution of welfarist regimes, the advent of disability statistics also reflects what Stone (1984) would describe as the subjectivization of disability within needs-based systems. In other words, disability data are influenced by the normative contexts in which disability is understood within societies. In the following sections, we highlight the cases of the Singapore and Australian censuses to discuss the implications and ramifications of these modern data collection efforts from the standpoint of disability data justice.

Singapore: Late to the Game?

Singapore's case presents a key exemplar of the normative logics at play in enumerating disability through censuses. We return here to the anecdote introduced at the start of this article, where we highlight Singapore's introduction of disability categories in its 2020 population census (Tan, 2021), which also reflects its commitment to the Convention. However, a closer look at the history of enumerating disabled people in the country suggests that disabled people and their organizations have advocated for the counting of disability since at least the late 1980s, yet nothing was done in the intervening years up to 2020 (Advisory Council on the Disabled, 1988). The Advisory Council on the Disabled in 1988 noted the importance of collecting statistics about disability so that services can be properly provided. In 2007, the first Enabling Masterplan, a state-initiated roadmap charting the steps needed to achieve an inclusive society, also

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highlighted the importance of determining "the prevalence rate of disability, including possibly conducting a national census" (Ministry of Social and Family Development, 2007, p. 13).

In this context, the 2020 Singapore Population Census was a culmination of these earlier efforts. The 2020 Census adopted guidelines from the Washington Group on Disability Statistics to assess individuals' difficulties across six key domains: seeing, hearing, mobility, remembering, self-care, and communicating (see Appendix A for the questions used). These guidelines, encapsulated in the Washington Group Short Set on Functioning, are grounded in the World Health Organization's International Classification of Functioning, Disability, and Health framework. The Short Set thus represents a shift away from the medicalization of disability (e.g., in its reliance on avowedly medical certification and diagnosis) toward a bio-psychosocial model and is the internationally agreed standard on collecting disability statistics (Washington Group on Disability Statistics, 2020).

The way the Short Set defines disability, however, is the crux of the matter. In the same media report referred to in the introduction, there was also considered concern over the measurement of "disability." The headline of the article—"Why 'disability' word not used in Census 2020, even as these numbers reported for the first time" (Tan, 2021)—paid heed to this issue. The Department of Statistics, which conducted the census, explained that:

> A person who faces difficulties in a basic activity as defined in the Census of Population 2020 is not necessarily a person with a disability . . . For example, a person may say that he or she has a lot of difficulty remembering but he or she may not be medically diagnosed as having a disability. (Tan, 2021, paras. 2–3)

This clarification is significant for several reasons. While the Washington Short Set, in its focus on functioning, aims to move away from the medicalization of disability, there seems to be in Singapore still an overt understanding of disability as medicalized. As Zhuang (2016) highlights, the definition of disability in Singapore's Enabling Masterplans, and also across various disability policies administered by the Ministry of Social and Family Development, continues to describe it with medical language and is reliant on medical professionals to gatekeep entry into disability categories. This strict medical definition of disability also contributes to the possibility of a lower prevalence, given how particular conditions, such as mental illnesses, might not fall under the rubric of disability in Singapore (Zhuang, 2016). More importantly, how disability is understood within broader Singapore society differs from that set out by the Census and the Washington Short Set.

The use of the Washington Short Set, with its focus on self-reported functional assessment, is also not without its problems. As Kuper, Davey, Banks, and Shakespeare (2020) explain, how the questions in the Short Set are answered is open to interpretation and may affect the prevalence of disability reported. Notably, the Short Set does not account for disabling mental health conditions and those with developmental disabilities (UNESCWA, 2022). This may account for the lower than usual prevalence rate of 2.5%, as reported in our opening anecdote (as opposed to the global prevalence rate of 16% estimated by the World Health Organization [2023]). In the context of data and disability justice, undercounting disabled populations may have implications on policy planning as well as resource allocation, which in turn has

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consequences for disabled people's inclusion. More importantly, the focus on activity limitation falls back on questions of body/mind impairment rather than questions of social and economic participation or barriers. As Oliver (1990) suggests, census questions should be designed to focus on barriers in society and environment, rather than on one's health/impairment. Ultimately, disability is still medicalized in policy contexts, despite the focus on counting differently.

Australia—New Data Initiatives, but Continued Problems?

In Australia, disability data collection has had a longer history than Singapore. Population-level data around disability were collected from 1981 in the Australian Bureau of Statistics' Survey of Disability, Ageing and Carers. The Survey of Disability, Ageing and Carers is regarded as the most comprehensive of all disability data collected and has since been repeated in 1988, 1993, 1998, 2003, 2009, 2012, 2015, 2018, and 2022. Government censuses also began to collect disability data from 2006 onward (Australian Institute of Health and Welfare, 2019, p. 126). Crucially, both data sets provided fundamental information about disability, which served to illuminate issues that disabled people faced, including general inequalities and intersectional oppression (Man, Wade, & Llewellyn, 2017).

In the context of the universalization and international homogenization of disability data, the Australian Bureau of Statistics piloted the trial of the Washington Short Set questions in 2016, as part of a Supplementary Disability Survey conducted on a sample of respondents from the 2015 Survey of Disability, Ageing and Carers. Compared with the Washington Short Set, which utilizes six questions to identify difficulties experienced with six functional domains, the Survey of Disability, Ageing and Carers is an "extensive set of questions designed to identify disability and the underlying conditions causing disability. A large number of these questions are used to establish if a person is restricted by disability and is in need of assistance" (Australian Bureau of Statistics, 2016, p. 7).

As the Australian Bureau of Statistics (2016) explains,

> A person has a disability if they report they have a limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities. In contrast, using the [Washington Group] Short Set in the [Supplementary Disability Survey] a person is identified as having disability when at least one domain is coded as a lot of difficulty or cannot do it at all. (p. 7)

In comparing the two surveys after the pilot, the Australian Bureau of Statistics (2016) found that "just over one quarter (26.9%) of people with disability in the [Survey of Disability, Ageing and Carers] were identified as having a disability in the [Supplementary Disability Survey]" (p. 1). In other words, the Short Set (as used in the Supplementary Disability Survey) was unable to capture the full range of people who have a disability, as identified in the more comprehensive Survey of Disability, Ageing and Carers. Significantly, the use of the Washington Short Set has not been repeated in the Australian context.

We note that while the Survey of Disability, Ageing and Carers offers a more comprehensive view of disability, it ultimately also relies on medicalized views of what disability is. In the 2022 version (Australian

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Bureau of Statistics, 2024), the survey also collected a long list of health-related conditions ranging from different types of cancer to mental health conditions such as "depression," "mania," and "bipolar disorder"; "autism spectrum disorders"; and amputations (among others). The survey also contained a subcategory that captures 18 types of disability (Table 1). This is supplemented by questions on the "broad area of activity" that one may require assistance or experience difficulty in, such as mobility, self-care, oral communication, health care, and reading/writing. Here, as in the Singapore case, despite its broader remit and categories captured, disability in the Australian census ultimately falls back on individual limitation rather than societal barriers.

Table 1. 18 Subtypes of Disability in the Survey of Ageing, Disability, and Carers 2022 (Australian Bureau of Statistics, 2024).

Types of disability	
01	Loss of sight
02	Loss of hearing
03	Speech difficulties
04	Breathing difficulties
05	Chronic or recurrent pain or discomfort
06	Blackouts, seizures or loss of consciousness
07	Difficulty learning or understanding things
08	Incomplete use of arms or fingers
09	Difficulty gripping or holding things
10	Incomplete use of feet or legs
11	Nervous or emotional condition
12	Restricted in physical activities or work
13	Disfigurement or deformity
14	Mental illness
15	Memory problems or periods of confusion
16	Social or behavioural difficulties
17	Head injury, stroke, or other acquired brain injury
18	Other disability type(s)
19	Not applicable

Beyond how disability is captured, we note encouraging developments in the use of data in the Australian census in ways that lend itself to big data analytics. In 2019, the Australian Institute of Health and Welfare (2019) moved to institute minimum data sets for Commonwealth/State Disability Agreement Services and, together with other population-level data, provided the basis for development of disability services. This, of course, occurs within a larger transformation of disability service provision effected with the introduction of the National Disability Insurance Scheme from 2013, which sought to provide direct funding to disabled people so they can acquire services they need (National Disability Insurance Agency,

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2024). It is also within this context that we can understand moves to develop the National Disability Data Asset.

The National Disability Data Asset was seen as the means to bring together the two disability data sets that are held under and conducted by the Australian Bureau of Statistics and the Australian Institute of Health and Welfare, as well as with other disability data sets such as the National Disability Insurance Scheme and those held by state-level agencies (NSW Government, 2024). The National Disability Data Asset, as various government websites explain, will integrate anonymized data of disabled people and ultimately benefit and support disabled people and their carers (Australian Government, 2024). Specifically, the integration of these data sets is to be done through an infocomms technology solution that allows for research and analysis in a secure, scalable, and controlled environment (Australian Bureau of Statistics, n.d.).

The bringing together of data, in particular big data sets that pertain to disability, bodes well, especially in tracking and monitoring the wide-ranging goals Australia's Disability Strategy 2021–2031 has set out to achieve. However, the National Disability Data Asset has also come under criticism. The Disability Advocacy Network Australia notes the Data Asset fails to properly address the intersections of disability with other kinds of disadvantages and marginalized identities, and it ultimately fails to hold disability service provision accountable to disabled people (Disability Advocacy Network Australia, 2023, p. 4). More pointedly, in its report on community responses to the National Disability Data Asset, the Sydney Policy Lab (2022) notes that disabled people, while supportive of the Asset, were concerned about the erosion of fundamental disability rights. Specifically, disabled people called for disabled leadership of the National Disability Data Asset, as well as continued disabled governance of its day-to-day operations. Only then could there be what the Policy Lab calls "No Data About Us Without Us" (Sydney Policy Lab, 2022). In these critiques, it is clear there is an urgent need to also address the sociocultural barriers that inhibit disabled people from full participation in society, beyond data.

Close to two decades ago, Goggin and Newell (2005) spotlighted how Australians with disabilities continued to face discrimination in their everyday lives despite an increase in funding for disabled people in Australia and improvements such as curb cuts, accessible public toilets, and better language use, among others. This observation continues to hold true today, reflecting the lived experiences of disability, despite the increased focus on understanding disability data and their possible impacts. The nonchalant and lackluster manner in which the current government has responded to the some 222 recommendations to improve the rights of disabled people made by the recently concluded Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, as well as the lack of consultation in its proposed reforms for the National Disability Insurance Scheme (Evans, 2024), highlights how disabled people's voices continue to be sidelined and marginalized even as major efforts are being made toward their inclusion in society (Department of Social Services Australia, 2021).

A disability justice approach to data thus calls our attention to the structures that may inhibit disability. As we highlight, when disability is counted within large data sets—in big data associated with both emerging technologies and censuses—it can still be located within normative structures and informed by problematic discourses. As we show in our case studies of Singapore and Australia, despite two differing

https://doi.org/10.65476/192t5w27

approaches to disability data collection in the censuses, when considered within the broader societal discourses of disability, they highlight key issues that are detrimental to rights inclusion—something that is evident, but still little understood, in big data.

Toward Disability Data Justice?

In both Australia and Singapore, despite efforts to integrate disability data into census reporting and analysis amid the broader landscape change toward a more inclusive international regime, normative (and problematic) discourses of disability continue to inform, and put paid efforts made toward integration of disability within data. As we have shown, a disability data justice approach brings attention to the normative structures that disability can be placed in, within both national contexts and international regimes. This bears out the point made by Rohman, Pitaloka, Erlina, Dang, and Prastyani (2023), in their discussion of disability data in the Global South, that "while deconstructing ableism in the society may take time, mitigating irrationalities in disability data use, as well as creating inclusive response plans, is a matter of political commitment" (p. 4).

Across the Asia-Pacific region, big tech and its products, including giant regional digital platforms and app companies such as WeChat, Line, Grab, and Gojek, are increasingly present in everyday life (Goggin, 2021; Zhuang et al., 2025). While not the main focus of this study, there are lessons from our discussion of population censuses that apply to the data collected by these tech companies. As Rohman, Dang-Pham, Pitaloka, Erlina, and Prastyani (2024) note in their discussion of Vietnam, there is an urgent imperative for privacy laws to also affirm disability rights. Privacy has been a long-standing issue for disabled people in relation to data collected, held, used, and disclosed by governments and their agencies (Yang, Zheng, & Yao, 2024)—the classic domain of privacy concerns and the law (and regulation to address these) that evolved from the 1970s onward. There are also complex issues about privacy, disability, and publicity in terms of disabled people's control over disclosing their disability identity (Harris, 2021).

What is also unclear is the interplay or contradiction between internal policies of some big technology companies, which have sought to stake out leadership positions on "good data" and privacy policies, and disability and the specific national laws on data privacy (Corning, 2024). In all of this, it is notable that, as of yet, disability has not prominently figured in policy, law and regulation, discussion, or research—so this is an important area urgently in need of future study. There can, for instance, be paradoxes involved in disability data discourses and privacy, highlighted in the way increased accessibility is used as a rationale for deployment of technologies that also underpin greater surveillance of disabled and other populations (Pucciarelli & May, 2023). As well as inconsistent implementation of laws and regulations to protect user data in the Asia-Pacific region and much of the Global South, especially when it comes to addressing disability data concerns (Rohman et al., 2024), there is simply not a great deal of visibility or attention evident to date.

So what forms can disability data justice take? Critiquing big tech's approaches to mapping access, Hamraie (2018) describes how these tend to "be 'big data' projects operating at the global scale" (p. 464), based on certain assumptions and problematics—the sighted wheelchair user—that perceive disabled

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populations as essentially homogenous. Explaining a project on mapping access initiated at their university, Hamraie (2018) notes the ways in which access mapping, when led by disabled people themselves, can establish disabled people as noncompliant users and create opportunities to challenge dominant discourses about accessibility.

This theme of noncompliance takes on greater valence, given how this resistance can also be generative. For Banner (2018), amid the overwhelming power (economic and otherwise) and logics of big tech, noncompliance and resisting or refusing to partake within big data sets offers different possibilities for building crip futures. Reading Jesse Ball's novel *Census*, Hall (2025) highlights how the protagonist—a census taker—privileges those with disabilities in their duties, deliberately skewing data collection to create more equitable systems for those with disabilities.

Still, we caution against such an approach, noting that while resistance has proven historically useful in disabled people's advocacy (e.g., in legislating access), overt resistance might prove detrimental to the overall goal of inclusion. Key international milestones, such as the Convention and the implementation of the Washington Group Short Set, while beginning from a place of resistance, are ultimately reliant on collaboration and cooperation. More importantly, while a disability data justice approach can draw attention to the ways disability in big data comes to be embedded within normative discourses, true inclusion can only be achieved when disabled people have choice and control over their lives. In other words, it is not only necessary to collect disability data and ensure the provision of disability services. Achieving data justice means also ensuring disabled people are among those who govern, lead, control, and also analyze data.

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Appendix A: Abridged Questions From the Singapore Census 2020 (Department of Statistics Singapore, 2021, pp. 121–122)

1) Does this person have difficulty seeing, even if wearing glasses?
2) Does this person have difficulty hearing, even if using a hearing aid?
3) Does this person have difficulty with body movement activities such as walking or climbing steps, or transferring from bed to chair/wheelchair (and vice versa)?
4) Does this person have difficulty remembering or concentrating?
5) Does this person have difficulty with self-care activities such as washing all over (bath/shower) or dressing, feeding, or using the toilet?
6) Using this person's usual (customary) language, does he/she have difficulty communicating, for example, understanding or being understood?

☐ No—no difficulty
☐ Yes—some difficulty
☐ Yes—a lot of difficulty
☐ Cannot do at all

https://doi.org/10.65476/192t5w27