

Living with Disability during the COVID-19 Pandemic in Japan and Australia

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Abstract: In recent years, scholars, activists, and other interested parties have written about how the COVID-19 pandemic has affected diverse populations of disabled people. Although well-intentioned, their curations have been subject to numerous constraints, (re)producing projects that have empowered some, but not all, impaired individuals across the Asia-Pacific region. In this article, the co-authors reflect on their own experiences of disability in Japan and Australia. Using autoethnography, they suggest how increased attention to the diversity of experience and the mitigation of stigma might enrich our understanding of the lives of impaired individuals, as well as the social structures, legal systems, and built environments surrounding them in different contexts. This logic might be meaningfully adopted by researchers of other minority demographics, figured in terms such as age, race, gender, class, and ethnicity.

Keywords: disability, inclusive society, Japan, Australia, COVID-19 pandemic.

Introduction

In recent years, scholars, activists, and other interested parties have written about the ways that the COVID-19 pandemic has affected diverse populations of disabled people. Consider a report published by a journalist from the BBC in February 2020, which described how a boy with cerebral palsy in Hubei, China died alone in his family home after his father was forcibly quarantined upon testing positive for the novel coronavirus (2020). The article investigated how the disabled child was abandoned, starved, and dehydrated due to officials' gross mismanagement of his care. At the time, it set a shocking tone for readers around the world, who at the time had yet to fully grasp the extent of the public health crisis. While the article's compelling prose may have served the BBC's agenda of "hooking" readers and delivered an authentic account of life and death during the pandemic, its extreme story and subject matter invite questions about disabled experiences during the global pandemic: in what ways did the pandemic help or hinder the lives of disabled people?

In this article, we unpack several factors that influenced the ways that the authors framed their experiences during COVID-19 as scholars and affected parties in Japan and Australia. More specifically, we use autoethnography to demonstrate that there is no one single experience of the pandemic, given the diversity of disabled lives, and that pandemic isolation has in some ways has created a window by which nondisabled people might be able to reconsider the effects of stigma associated with physical and cognitive impairments.

Our research contributes to numerous academic disciplines and areas of practical expertise. For scholars of the Asia-Pacific region, it shows how critical analyses of disability curations during the pandemic may afford us greater insight into barriers faced by impaired individuals, as well as their friends, families, and colleagues. Indeed, increased study of the exclusionary aspects of curations might help us to identify and resolve inequalities in built environments, education, employment, entertainment, and healthcare systems in different cultural contexts. We consider how the removal of obstacles currently hidden by

curatorial omissions may lead to increased independence for disabled persons and liberate individuals who help support them: women, children, older people, professional care workers and others. In fact, our study's logic of overcoming curatorial omissions through autoethnography might meaningfully be extended to such "caregivers", whose experiences of hardship are often effaced in favour of disabled persons themselves. Accordingly, our project also offers contributions to scholars interested in problems faced by diverse minority demographics, as well as affiliated social movements, economic entanglements, and technical interventions.

Disability studies scholars, as well as those in gender studies, postcolonial studies and other fields, know that marginalised voices matter: who better to tell stories of marginality than the marginalised themselves? Autoethnography as method is particularly suited for disability studies as it privileges the lived experience from the *tōjisha* perspective (*tōjisha* means "person concerned", and it is used to indicate an emic perspective). Furthermore, as Smith and Sparks write, "society and culture "speak themselves" through an individual's creation" (2008, 18). It is our contention that our recollections of living with disability during the early days of the global pandemic provide alternate viewpoints to commonly understood discourses about what life was like in Japan and in Australia during lockdown(s). Despite the differences in our experiences, we found sharing stories between us to be empowering; this sentiment was reflected in Kafer's definition of disability memoirs as "alternatives to the narratives of eradication and cure" often found in fictional portrayals of disabled lives (2013, 84). Narratives of disability can also highlight the social embeddedness of the person and their impairment, rather than isolating them within an individual diagnosis (Smith and Sparks, 2008: 18). The authors created their autoethnographies through discussion-based recall (e.g., speaking with family members to enhance personal memories; comparing our experiences to prompt further memories and analytic viewpoints). With these framings of autoethnographic narratives in mind, the authors ask readers to consider the possibilities offered by a conscious and reflexive curation of any kind of narrative, to refine future research in disability studies, area studies and other fields.

We begin by setting the context for our autoethnographies of disability during the COVID-19 pandemic in Tokyo, Japan and Melbourne, Australia. As we note, the pandemic served as a mass-disabling event, restricting access to built environments, education, employment, entertainment, and healthcare services for both disabled and nondisabled individuals alike. Shared experiences of inaccessibility allowed for the formation of empathetic relationships across demographics to a certain extent. However, differences in personal circumstances and competition for resources meant that some realities of the pandemic were hidden from public view and failed to be accounted for. By reflecting on our own struggles with exclusion during the pandemic as affected parties, we highlight some of the factors that complicated newly formed empathetic relationships and showcase an impetus for curations of disability.

The COVID-19 pandemic as a mass disabling event in Japan and Australia

As the COVID-19 pandemic spread throughout the world during the early months of 2020, policymakers in Japan and Australia drafted a series of infection prevention protocols that restricted individuals' access to education, employment, entertainment, healthcare, and other sectors of society. For example, in February, the Japanese Ministry of Health, Labour, and Welfare published guidelines which recommended, but did not require, that all residents practice social distancing, use personal protective equipment, and avoid large gatherings if possible. (MHLW 2020) Meanwhile, Australia became a "Hermit Kingdom", as federal and state governments instituted strict border controls (Trigger, 2022); set density limits; mandated masks in public; and implemented contact tracing efforts. The specifics of such policies were shaped by cultural contingencies, including, but not limited to, economic conditions, environmental circumstances, and pre-existing legal structures. In this section, we trace how nondisabled persons in both contexts struggled with restrictions on their agency due to pandemic-era policymaking to reveal the roots of their empathy with disabled people. While there was a potential for empathy born out of shared experiences of inaccessibility

and new conceptions of personal vulnerability in the face of a new human pathogen, our autoethnographies illuminate the commonalities and the differences between the lived experiences of the two demographics.

To more fully understand how pandemic-era policies structured the lives of nondisabled people in Japan and Australia and allowed them to establish empathetic relationships with disabled individuals, we can learn from nondisabled stories drawn from local media outlets. As news articles in *The Japan Times*, *Nikkei Asian Review*, and related publications make clear, governmental attempts to contain the coronavirus in Japan contributed to major hardships for members of the public who struggled to adapt to a rapidly changing landscape. Consider mandatory school closures, which began in February 2020. (MEXT, 2020) With little warning, parents were required to care for their children during work hours, leading many to promote remote education and transition to telework. (Takahara, 2020) Such technological solutions seemed like a promising way to overcome the social distancing problem created by the pandemic but frequently failed to pan out in practice as Japan historically lacked a “telepresence” infrastructure. Labourers in different fields had difficulty adjusting their in-person activities to an online format that demanded new modes of participation. Indeed, paired with the closure of public facilities, “panic buying” of protective equipment, and other problems, it is not surprising that such issues magnified stress and led to a sharp increase in domestic violence cases. (Masangkay, 2020, Ryūkyū Shimpō, 2020).

Articles in the Australian mainstream press (*ABC News*, *The Age*, *The Guardian*, *The Australia* and others) similarly reported on the pandemic’s restructuring of daily life. Pandemic policies impacted a nondisabled person’s life in a multitude of ways: during the early days of the pandemic, Australians panic-bought toilet paper (Wright, 2020), cursed their wavering broadband during Zoom meetings (Taylor, 2020), argued with partners over housework (WGEA, 2020) and worried about children not making academic progress in their Microsoft Teams classroom (Heffernan, 2021). So much was the demand for online services (due to store closures) that in 2020 Australia Post reduced its metropolitan delivery in Victoria to every second day (McGhee and Kewley, 2020). Many local shops closed when takeaway income did not meet their

needs (Karp, 2020). Families and friends experienced breakdowns when their views regarding the vaccine rollout differed (Jacques, 2021). Melbournians in particular (as the most locked down city in Australia) found themselves increasingly isolated in ways they had not previously known; one could say that for the first time, they felt “disabled” (Gibbs, 2022).¹

Nondisabled individuals were not the only ones to be disempowered during the early days of the pandemic; new light was shown on the experiences of disabled people during the pandemic. The *ABC*, for example, asked its readers to look to disabled people as exemplars of human resilience during difficult times by telling “inspiring” stories of “pandemic positives” (Bartholomew and Salmon, 2021).² Meanwhile, an article in *The Japan Times* argued that disabled people had much to offer when it came to teaching survival strategies and ways to make the best of limited resources. (Bookman and Peckitt, 2020) Disabled persons in both countries, for their part, often tried to capitalise on such rhetoric by arguing that an inclusive society for impaired individuals would benefit everyone (Japan Disability Forum, 2020; WDV 2021, p. 3). For a time, it seemed as if disabled and nondisabled people in both countries would come together and lobby for social change. But even as coalitions of “activists for accessibility” began to appear, there were problems that impeded their campaigns: notably, lack of awareness and competing interests.

Disabled Experiences of the Pandemic

¹ Gibbs notes that normative lockdown can resonate with some aspects of the disabled experience: “Non-disabled people talked about how hard being in lockdown was, how much they missed seeing people, how difficult they were finding being on screen all day. This was my life they were talking about, my exact life.” (2022)

² While these “inspiring” stories were part of an ABC campaign to celebrate the International Day of People with a Disability (3 December) to bring widespread attention and praise to these accomplishments, we note that these stories can veer uncomfortably close to ‘inspiration porn’ (for more on this term, see Young 2014).

Living with disability in Japan and Australia comes with numerous obstacles and challenges. Government data shows that disabled students make up only 1% of enrolment in Japanese universities, and more than half of all large private companies are failing to meet their legally mandated hiring quotas for disabled people (2% of employees). (MHLW, 2019; JASSO, 2021) Seventeen percent of Australian disabled people have a university degree, compared to 35% without a disability. (AIWA, 2020, p. 234) Disabled Australians also grapple with access to “effective healthcare” due to “inadequate transportation, failure to provide assistance with communication, and discriminatory attitudes among healthcare staff” (VicHealth, 2012, pp. 3–4). During the pandemic, disabled people in both countries experienced exacerbated barriers. To highlight some of those barriers, we narrate our stories of the pandemic in this section. While limited in many respects, our stories suggest how individuals with specific disabilities and their families struggled to secure sufficient and appropriate access to medical care, independent living services, and professional development opportunities as the virus spread. Such obstacles were often invisible to activists for accessibility (with and without disabilities), who did not live with impairments or regularly interact with persons with particular conditions.

Mark’s Story

Mark recalls the waves of anxiety that flowed over him as he grappled with access to medical care in March of 2020, just as the pandemic began to pick up in Japan. Two months had passed since the failed quarantine of the Diamond Princess cruise ship off the coast of Yokohama, and the virus was on everyone’s minds as schools and workplaces went online. As an immunocompromised individual, Mark was particularly worried about venturing outside due to fear of infection and had done his best to isolate himself inside his apartment. Indeed, Mark was lucky to live in Odaiba: an artificial island which was removed from regular flows of traffic that had only a few residences for international researchers. Mark’s decision to move to the island had been driven by a lack of wheelchair-accessible housing in central Tokyo. And while he was frustrated at first by limited shopping and transportation options, Mark was suddenly grateful that his “abandoned amusement

park” provided some shelter from COVID. As Mark slowly began to take comfort in his “self-imposed exile”, however, disaster occurred. Mark contracted a 37.8°C (100°F) fever and had to ask himself if it was worth risking a trip on public transit to visit the nearest hospital capable of treating him, which was one hour away. There were closer hospitals, but due to the specifics of Mark’s condition (namely, his heart transplant) most were unwilling or unable to treat him. After much agonising, Mark eventually decided to go to the hospital and was monitored for three weeks due to intestinal problems. However, the duration of Mark’s stay was marked by fear of infection from his roommates, who were not socially distanced from him due to spatial limitations and financial constraints.

Arguably an even greater problem for Mark than access to adequate and appropriate medical care in the early days of the pandemic was access to independent living services. As a person with a rare neurodegenerative muscle disease that restricted his mobility, Mark needed assistance with tasks like sitting up, dressing, eating, drinking, toileting, and bathing. Before COVID-19, Mark carried out such tasks with support from professional caregivers, whose wages were paid for by the Japanese national government and his local municipality. But even then, Mark had a hard time recruiting willing workers due to his remote location and issues of scarcity connected to Japan’s rapidly ageing population and shrinking labour force. The coronavirus further complicated Mark’s care networks as some of the companies that he had contracted with refused to send caregivers or shut down due to concern about infection. As a scholar of disability in Japan, Mark could not help but sympathise with their situation: caregivers and clients alike were scared that their trips outside would put both parties at risk. Still, as a person in need of independent living services, Mark found himself in a dire state. There were days when, in the absence of care, Mark woke up gagging on saliva without the capacity to sit upright and clear it out on his own, leading to prolonged periods of discomfort. There were also times when Mark almost choked on food and had to sleep on soiled sheets. Mark wanted to tell other people about his struggles, but there too he encountered problems.

Perhaps the most frustrating part of Mark's experience of COVID-19 was not the lack of access to medical or care services, but rather opportunities for professional development. Without the former, Mark would face bodily hardships that were largely personal in nature. Without the latter, however, he would lack the ability to contribute to ongoing conversations inside and outside the academy about disability that affected not only himself but others, too. The psychological burden of knowing that there were other disabled persons in Japan whose challenges far outweighed his own but lacked the necessary resources to participate in such conversations was immense during "normal" times but exacerbated tenfold by the pandemic. Mark felt compelled to gather data about their experiences and work with them to develop collaborative projects that would help eliminate some of the barriers that they encountered. Despite his resolute desire to help individuals with less privilege than himself, however, Mark realised that he could not safely leave his house, let alone access archives that had closed. Indeed, Mark failed to obtain books, journals, and other materials necessary for his research, and noted that his scholarly and public writings gradually narrowed in scope as time passed. Would Mark be able to compete for a permanent academic position at his present pace and ensure that he would have sufficient resources to continue his access-making in the future? Thinking about such questions, Mark became incredibly frustrated and grappled with bouts of depression as he lamented the setbacks that he and other scholars of disability endured. Mark resolved himself to do something – anything – to highlight the issues they were facing.

Carolyn's Story

Carolyn is not disabled, but lives with and cares for her twenty-two-year-old daughter, Sora, who has multiple disabilities and complex medical needs due to a rare chromosomal disorder (trisomy 4p). Her lived experience of disability arises from her proximity and strong emotional ties to a disabled person. For those with significant disabilities (and especially so in the case of intellectual disability) parents are often the first and the loudest, if not the only, advocates for these people (see Panich, 2003). Carolyn remembers exactly

when the feeling of dread started. A respected colleague emailed her in mid-March 2020 about an American company which sold bipap machines with international delivery. “You better get one for Sora!” they wrote, after having ordered one for their older spouse. While others were grabbing up rolls of toilet paper, thinking of maintaining their levels of comfort, Carolyn and Sora were facing issues of life and death. Instead of stockpiling comfort food, Carolyn’s husband bought a pulse oximeter. As images of overflowing hospitals in Europe and the Middle East pervaded the evening news in late March 2020, she knew that if Sora did contract COVID-19, she would need significant medical intervention, and fast. Furthermore, Sora’s non-speaking modes of communication were not specific enough to communicate the urgency of medical need, highlighting the importance of communication as a barrier to medical care.

For disabled people living independently, the experience of ‘Lockdown 1.0’ from March to June 2020 saw a crumbling of home and community services in Melbourne. Sora’s in-home respite was the first to go; then short-term accommodation and her day service closed. During the first lockdown, Sora had 59 consecutive days with no services. She had biweekly occupational and speech therapy sessions via Zoom, used to create social stories to communicate to Sora a vastly different reality. These helped her make sense of not only the sudden changes in routine, but also the loss of contact with carers and peers, as they are her most important relationships outside her immediate family. During the second lockdown, Sora’s day service opened under very different standards which allowed them to qualify as an “essential service”. They met the state’s COVID-safe criteria by introducing personal protective equipment for workers, dividing the grounds with temporary fencing to minimise mingling, and reducing client numbers to allow social distancing. Only a small number of younger participants who still lived at home (with limited primary contacts) were allowed back. While the redefinition of disability support as an “essential service” during the second lockdown was a welcome shift, it is possible that this recognition was a quiet concession that the uncertain wellbeing of disabled people locked down in private homes was a graver risk.

Sora's independence skills, which had been developing through short accommodation and other community access programs, were also put aside; she was returned to the social role of "child at home", and her parents were responsible for her care 24/7. The sudden pivot to "work from home" meant creating pre-recorded lectures and delivering four Zoom discussion sections per week, which sometimes clashed with Sora's home care. Research plans fell by the wayside: Carolyn abandoned a multi-partner, trilateral research site project when the grant program was suspended in April 2020, and the project itself became untenable as it required travel between Boston, Kyoto and Melbourne. Carolyn's sabbatical, set for the latter half of 2020, was postponed. Meanwhile, to combat a gaping hole in budgets, staff were presented with a variation in their "enterprise bargaining agreement" (contract with the university) which asked them to take a salary reduction for a year plus the offering of voluntary separation packages which would be available to targeted parts of the university deemed unsustainable. Tenured positions became precarious; entire programs within the faculty were closed. Carolyn's experience as a primary caregiver and an academic had seen many ups-and-downs over the years, but the pandemic threw into high relief problems that had been bubbling under the surface for some time, and she felt it was time to do something about it. She invited Mark to give an online seminar at her department to talk about what the pandemic meant for people with different kinds of disabilities (e.g., Mark's experience versus Sora's) and in different countries (Japan versus Australia).

Telling disability stories

Living with disability meant that Mark and Carolyn knew the pandemic was endangering people's wellbeing and even their survival. As scholars, they had information to share, strategies to suggest, and stories to tell. However, their stories represented only slivers of reality. How should they strike the balance between responsible storytelling and personal motivation? What should be said, and what should be left unsaid? In constructing their narratives of the pandemic, and below are some of the challenges they confronted, and how they dealt with them.

Writing Mark's Pandemic Story

One set of challenges that Mark grappled with as he tried to curate the experiences of disabled persons in Japan during COVID-19 was tied to issues of representation and scope. Whose voices should he incorporate into conversations about equity, access, and inclusion? How might he balance his discussions about individuals with diverse bodies and minds? And what could he do to appropriately address the barriers that such individuals encountered? There was no clear-cut answer to these questions as the pandemic began to spread in 2020, so Mark created his own method based on his work as a historian and consultant. By analysing government records, newspaper reports, and documents from disability welfare organisations alongside personal testimonies collected through crowdsourcing technologies, Mark aimed to mitigate biases to the greatest extent possible and display a range of realities. However, Mark ultimately had to gather sources from online archives due to concerns about infection and developed a series of talks that reflected the interests of specific stakeholders. As a scholar of disability, Mark was keenly aware that there were likely perspectives missing from the presentations that he gave due to social, political, economic, and cultural barriers that stopped individuals with various impairments from sharing their accounts and opinions. For example, lack of access to assistive communications technologies might have prevented deaf, blind, or mobility impaired persons from contributing to the materials that he examined. Mark tried to highlight the possibility of such exclusions for his audiences each time he gave a talk, but even then, he could not speculate about all the populations he might have left out.

Mark was also sensitive to the venues where he spoke and the listeners who inhabited them. As many of Mark's disabled interlocutors were exposed to life-threatening risks during the early days of the pandemic, he was invited to speak to multiple and diverse audiences: for instance, scholars, activists, policy makers, medical specialists, and government officials. Each audience came to Mark's presentations with their own suppositions about the status of disability welfare in Japan and asked targeted questions that

reflected their unique interests. In fact, Mark was often asked to speak on the grounds that he examined a rather narrow range of topics like inclusive education, population ageing, and the Tokyo 2020 Paralympics. Although Mark framed his discussions of those topics in ways that emphasised dynamics of diversity within Japan's disabled communities (for instance, highlighting how the pandemic had erected different kinds of barriers for students with physical and cognitive impairments), Mark was still constrained by his listeners' time and expectations about presentation content. Accordingly, Mark gave talks in which he did not cover all the issues he felt to be important. For instance, Mark became frustrated when giving a lecture about the relationship between the Paralympic Games and COVID-19 to a volunteer organisation for young adults, whose members insisted that he speak about the ways that the games would help Japan 'overcome COVID-19' rather than their role in exacerbating inequities and facilitating institutionalisation. While Q/A sessions at the end of that lecture and others like it occasionally allowed Mark to delve into the details of such problematics for his listeners, he was often unable to unpack all the connections and had to make strategic choices about curation on a case-by-case basis.

Perhaps the most difficult issue that Mark dealt with was determining how much of his own story that he wanted to share with his listeners. Mark knew that his experience of COVID-19 as an American wheelchair user living and working in Tokyo was not necessarily identical to or representative of others', nor was it relevant to all the targeted issues that his audiences wanted to address. And yet, Mark's personal and professional experiences did inform how he understood the pandemic and its consequences for diverse demographics of disabled people, so he thought it important to discuss them out of honesty and transparency. To pre-empt possible critiques, Mark bracketed his "self-presentations" with disclaimers about the dangers of assuming that his anecdotes were indicative of larger social trends in Japan. But still, Mark needed to decide which stories he was going to tell and why he was going to tell them, often on the fly and with little preparation due to unexpected shifts in conversation. Should Mark tell his listeners that he almost missed their talk because his caregivers were late due to concerns about disease transmission? Or explain how their

online meeting was something that he had longed for in the pre-pandemic times but was rarely able to arrange? Such questions about ‘self-insertion’ paraded through Mark’s mind each time he gave a talk.

Carolyn’s Writing of Sora’s Story

Carolyn’s situation was different in that she was trying to capture and communicate the experience of a young adult with an intellectual disability; she was wary of “speaking for” Sora, but knew hers (and her husband’s) were the only voices who could feasibly do so. She also worried about omission, as she tried not to focus too much on the very real dangers of respiratory failure should Sora become infected. Instead, Carolyn focused on stories of how Sora was the most *resilient* in the family. Carolyn explained how well Sora adapted to new routines, and that she was the only family member who did not experience ongoing existential fear about the pandemic. Carolyn did this to counterbalance the “disability as personal tragedy to be overcome” trope that so often pervades general discussions about disabled people’s stories. But how relevant was Sora’s story to other children and adults living with intellectual disabilities? Not living independently meant that during the pandemic, she relied solely on her parents as main carers, as opposed to others who had a wider circle of carers and could perhaps exercise more agency in their care decisions. Furthermore, Sora’s home was not in danger of default or closure, like some families who experienced severe economic fallout due to lockdowns. Carolyn was concerned about the omission of stories of disabled people living precariously or those who were locked away from loved ones in group homes but could not speak directly to their experiences.

Related to omission is the issue of self-censorship and even the censorship of others. This was apparent in Carolyn’s moderation of a peer-to-peer support group for trisomy 4p families and carers. In her own posts generally, Carolyn chooses to encourage and empower other parents, so as not to instil anxiety of a future that might not eventuate. In 2020, however, online exchanges took on a new tone, as different members took different approaches to the concept of “sheltering vulnerable people”. These decisions

represented both socio-economic status (who could shelter, and who could not) as well as personal views. When paediatric vaccine doses were first made available, parents of younger children asked for advice from older parents. A diverse range of opinions were posted, and most were respectful, but a complaint was made in late 2021 to the administrators when a user referred to the vaccine as “the death jab”. The administration team agreed that the wording was inappropriate and deleted the post, but Carolyn spent some days thinking that a ham-fisted response would alienate the very members to whom she wished to appeal.

Finally, Carolyn also worried about negative sentiments related to “competitive victimhood” (Young and Sullivan, 2016, p. 30). Many of her nondisabled colleagues and acquaintances expressed sadness or dissatisfaction at the stay-at-home orders. She felt their online performances of the lockdown were focused on idle complaints, bingeing Netflix and making sourdough starters. Carolyn wanted to judge them but had to remind herself not to. She understood that others were likely managing their own experiences of hardship during the pandemic, even if they did not vocalise them. Everyone – regardless of ability – was working with low physical and emotional resources at the time, and what appeared as trivial complaints to some might very well spring from genuine anxiety and distress. Indeed, Carolyn knew that lockdown life entailed different things for different people. Her family had spent the better part of 20 years subject to limited mobility due to Sora’s physical impairments and complex behaviour; the long lockdowns in Melbourne created conditions in which many of her friends and colleagues became aware for the first time of the personal experience of ongoing constraints.

Learning from Each Other: the benefits of diverse collaborations

Mark and Carolyn co-presented a Zoom webinar as part of a weekly schoolwide seminar series at Monash University in March of 2021. Carolyn felt pressured to present a positive view of her family life, for she had ongoing institutional liabilities that made her hesitant to divulge too much during the presentation – in other words, she wanted to be sure to mitigate any stigma that might arise if she was too honest about Sora’s life.

By contrast, as an “outsider”, Mark was relatively freer to express himself regarding his challenges during COVID-19.

During the presentation, Mark spoke about physical disability and accessibility issues in Japan during the pandemic, emphasising policy reforms which had preceded the pandemic, and obstacles to implementation. Meanwhile, Carolyn gave a more detailed account of her family’s experience of cognitive disability during lockdowns which had made her re-think definitions of social and medical vulnerability. Together, their two talks helped to showcase the diversity of the disabled experience of COVID in a way that evoked possibilities for comparative exchange: there were just as many commonalities as there were divides between geography and impairment type. While Mark and Sora saw the world differently from the presentation audience members, everyone’s lives had been turned upside down by the pandemic. Nondisabled listeners could process stories of disabled lives with new insight given their new experiences of limitations and vulnerability.

Working together provided Mark and Carolyn with another opportunity to think about possible inclusions and exclusions. In partnership, they could more fully represent a range of disabled experiences by linking their stories to specific kinds of impairments (physical, psychiatric, intellectual or sensory) as well as other intersectional identities (figured in terms such as age, race, gender, ethnicity and class). Following the presentation, they published a short article entitled “Empathy, Equity, and Empowerment: Lessons to Learn from Disability Studies During a Pandemic in Japan and Australia” (2021), which refined their arguments and allowed readers to work through details that might have been unclear in their earlier presentation. Ideally, readers would then incorporate concepts from their joint curation into individual curations and contribute to their own areas of specialisation and expertise.

While they tried their best not to fall back on overgeneralised and stereotypical presentations of hardship during the pandemic, they did feel constrained by many factors, including, but not limited to, diversity among stakeholders, efforts to mitigate stigma, and listeners’ cultural expectations. This holds true

as much for contemporary Japan and Australia as it does for other countries, and at different historical moments.

Conclusion

As noted in the introduction, the BBC report on a disabled sixteen-year-old Chinese boy who died of neglect during the early days of the pandemic in China (BBC, 2020) highlighted specific hardships faced by a disabled individual and his father in Hubei, but this curation was likely to be partial and incomplete. To fill out the picture and better represent the full diversity of disabled experiences in China (let alone other parts of the world), additional curations of disabled experiences are necessary. However, as we have argued, the sharing of such stories must be done with reflexivity and care. Using our stories of the pandemic in Japan and Australia as case studies, we have shown how factors such as diversity among stakeholders, audience expectations, and efforts to mitigate stigma can lead us to inadvertently (or knowingly) reproduce projects that speak to some but not all populations. Going forward, we argue that such constraints in the curation of disability (during and beyond the pandemic) must be identified and addressed to create a more inclusive disability pedagogy for practitioners in different fields, and we invite scholars to engage in this kind of reflection in other disciplines as well.

This article has focused on writing strategies for disability studies, but it has much to offer scholars in different fields. For academics of Japan and Australia, for instance, our research suggests that additional attention to disability curations (both individual and joint) might not only enrich our understanding of the lives of impaired individuals, but also their friends and family, as well as the social structures, legal systems, and built environments in which they operate. Furthermore, our emphasis on the exclusionary nature of curatorial processes might meaningfully be extended to include other minority populations in both countries, whose identities are figured in terms such as age, race, class, gender, and ethnicity. Consider how more deliberately constructed narratives of old age in South Korea, ethnic diversity in Malaysia, or women's lives

in Indonesia would enhance our understanding of demographic change, multiculturalism, and identity politics in these places. These are just a few possibilities that arise when reflective curations of diversity are used to start dialogues.

We invite others to initiate and participate in such dialogues, asking that they keep in mind social, political, and economic inequalities that might limit participation by other parties. Indeed, power imbalances between interlocutors can contribute to unidirectional curations of diversity, which can be more alienating than welcoming. This is clear in cases where authors may speak for (or over) individuals with intellectual impairments. Despite such discrepancies, or perhaps because of them, deliberate story telling is all the more essential. Through better communication, we can enhance our efforts towards equity and inclusion. These stories are always negotiated, but deliberate attempts at authenticity may help us to build mutual understanding between otherwise disinterested demographics. Reflective writing techniques, accompanied by a proactive stand that addresses power relations that divide inter- and intra-group identities, give speakers a platform to achieve effective social change.

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